

**Pilot testing models of task shifting for the care of  
severe mental illness in South Africa**

**by**

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# **Abstract**

## **Background**

Mental and substance use disorders cause significant disability worldwide. In spite of the availability of evidence-based treatment, non-adherence rates remain high in people with severe mental illness. Mental health services are however under-resourced, especially in low- and middle-income countries. Interventions that employ task shifting, the delegation of health care delivery tasks to less specialized health workers, have the potential to address this resource shortage. Community health workers, while an established and important delivery agent for task shifting in many forms of chronic illness, including mental illness, have lacked access to standardized structured training in mental health. Together with novel approaches such as mobile health, task-shifting interventions have the potential to improve adherence and clinical outcomes for MHSU, thus reducing the burden on stretched mental health resources.

While the evidence for the effectiveness of task shifting interventions is growing, it is unclear whether the combination of a task shifting intervention with mobile health would be acceptable and feasible in low resource settings. It is also unclear to what extent a structured mental health training programme would result in improved knowledge, confidence and attitudes amongst community health workers.

## **Methods**

First, I conducted an appraisal of current evidence for interventions delivered by non-specialist workers for mental illness in Sub-Saharan Africa. The aim was to characterize the types of such interventions that have been carried out in Sub-Saharan Africa, to ascertain extent of use of non-specialist workers; the outcomes explored; any acceptability and feasibility findings; as well as any efficacy outcomes. Second, I developed and piloted two

task shifting interventions geared at improving care for severe mental illness in Cape Town, and evaluated their acceptability, feasibility and preliminary effectiveness.

*Systematic review:* For the systematic review, eligible studies published prior to 21 June 2017 were identified by searching the Cochrane library, PsychInfo, and Medline databases; as well as the World Health Organization International Clinical Trials and Pan African Clinical Trials Registries. The bibliographies of study reports for all eligible trials were scanned for additional studies. Included trials were those of interventions a) delivered by non-specialist health workers for b) adult populations (18-65 years) with c) psychiatric disorders diagnosed in line with ICD or DSM classification systems in d) Sub-Saharan Africa. No restriction was placed on the nature of the psychiatric disorder.

*Pilot randomized controlled trial:* A pilot randomized controlled trial was conducted, in which 77 participants with severe mental illness were recruited from Valkenberg psychiatric hospital in Cape Town, with 42 randomized to receive the intervention and 37 to receive treatment as usual. In the intervention arm, a treatment-partner selected by the participating MHSU underwent a psychoeducation and treatment-partner contracting session. The intervention pair then received two text message reminders of clinic visit appointments monthly. The primary outcomes were acceptability and feasibility of the intervention, measured through qualitative interview and process evaluation at 3 months post-discharge. Secondary outcomes for efficacy were 1) adherence to the first clinic visit; 2) any readmission in the 9 months following discharge; 3) quality of life; 4) symptomatic relief; and 5) medication adherence. These efficacy measures were conducted at baseline and again at 3-month study review. Between-group comparisons were done using an intention-to-treat ANOVA analysis for efficacy outcomes.

*Community Health Worker Training Intervention:* My second task shifting intervention was a quasi-experiment evaluating whether structured mental health training would

improve the knowledge and skill of community health workers while improving their confidence and attitudes towards mental illness. A training programme was developed in partnership with the Western Cape Department of Health, and piloted with 58 community health workers who had not previously received mental health training. Mental health knowledge and skill were measured through the use of case vignettes and the Mental Health Knowledge Schedule (MAKS). Confidence was measured using the Mental Health Nursing Clinical Confidence Scale (MHNCCS), while attitudes were measured using the Community Attitudes Towards the Mental Ill Scale (CAMI). Measures were conducted at baseline, at the end of the training, and again 3 months after the end of training for the knowledge and skill measures. Daily evaluation questionnaires were used to establish acceptability, and a training evaluation questionnaire was used to obtain further acceptability data, as well as to establish feasibility of the training intervention.

T-tests and regression models were used to test changes in questionnaire scores before and after each intervention, adjusting for baseline scores. Quantitative data were entered and analysed using STATA 10.0 for the pilot randomized controlled trial and the R statistical programme for the CHW intervention, while qualitative data were managed and analysed using NVIVO 8, a qualitative analysis programme for all analyses, for which a grounded theory approach was used, followed by thematic analysis.

*Ethics and registration:* Ethical approval was obtained from the University of Cape Town Human Research Ethics Committee, Faculty of Health Sciences for the treatment partner and mobile health intervention (HREC REF: 511/2011) and for the community health worker training intervention (HREC 913/2015). Both interventions were registered on the Pan African Clinical Trials Registry (PACTR201610001830190 and PACTR201610001834198 respectively). Finally, Health Impact Assessment Unit clearance was obtained from the Western Cape Department of Health for both trials (RP168/2011 and WC\_2016RP59\_635

respectively). The systematic review was registered on the International prospective register of systematic reviews (PROSPERO) (CRD42017065190)).

## Results

*Systematic Review:* Due to heterogeneous methods and treatment outcomes, a meta-analysis was not possible. A narrative synthesis is thus presented. Fifteen trials of interventions delivered by non-specialist workers (5087 participants) were identified. In each of the trials, the intervention was acceptable and feasible, with preliminary efficacy findings favouring the interventions.

*Pilot randomized controlled trial:* The treatment partner and text message intervention components were acceptable. While the treatment partner and psychoeducation components were feasible, the text message component was not, as a consequence of several socioeconomic and individual factors. While efficacy outcomes favoured the intervention, they did not reach statistical significance due to the small sample size.

*Community Health Worker Training Intervention:* Mental health knowledge improved as demonstrated by improved diagnostic accuracy on case vignette response. Sixty-three percent of participants demonstrated improved accuracy in making a diagnosis, with a roughly two-fold increase in performance in these individuals. There was a significant increase in the average scores on the Mental Health Knowledge Schedule pre- to post training ( $t = -4.523$ ,  $df = 55$ ,  $p < 0.001$ ,  $N=56$ ). This improvement was sustained at 3 months after the end of training assessment scores ( $t = -5.0$ ,  $df = 53$ ,  $p < 0.001$ ,  $N = 54$ ). There was a significant increase in the average Confidence scores pre-intervention (mean SD): 45.25 (9.97) to post-intervention 61.75 (7.42), t-test:  $t = -8.749$ ,  $df = 54$ ,  $p < 0.001$ ,  $N=58$ ). Attitude scores ( $n=45$ ) indicated no change in authoritarian attitudes [mean (SD): Pre 27.87 (2.97); Post 26.38 (4.1),  $t = 2.720$ ,  $p\text{-value} = 0.995$ ], while benevolence [mean (SD): Pre 37.67 (4.46);



Post 38.82 (3.79),  $t = -1.818$ ,  $p\text{-value} = 0.038$ ] and social restrictiveness [mean (SD): Pre 24.73 (4.28); Post 22.4 (5.3),  $t = -2.960$ ,  $p\text{-value} = 0.002$ ] attitudes showed improvement pre- and post-training, as did tolerance to rehabilitation of the mentally ill in the community ( $t = 2.176$ ,  $p\text{-value} = 0.018$ ). Participants responded well to training, appraising it as acceptable and appropriate to their work. They expressed a need for a longer training programme with further training on substance use and geriatric disorders. Stakeholder participation was consistent and contributed to the feasibility of the intervention.

## **Conclusions**

A review of task shifting interventions by non-specialist health workers indicates that these have yielded positive outcomes for mental health service users in published trials. Such interventions have the potential for reducing the mental health treatment gap in low and middle income countries in a cost-efficient way. Further work is however required to develop specific treatment approaches for particular disorders, and to assess the outcomes of such interventions, including cost-efficiency measures. The measures of outcome used in this field remains somewhat disparate; the development of a common research agenda may assist in developing and replicating further investigations and generalising findings.

A treatment-partner intervention is acceptable and feasible in a low- and middle-income setting such as ours. Careful work is, however, needed to ensure that any additional components of such an intervention, such as mobile health, are tailored to the local context. Appropriately powered studies are needed to assess efficacy.

Structured training in mental health is acceptable and feasible in our setting. The training intervention led to an improvement in knowledge and skill amongst community health workers while improving confidence and attitudes. Participation of policy stakeholders was key in ensuring the success of the intervention. There is a need for interventions evaluating the outcomes of community health worker training to provide more

detailed descriptions of their training interventions. More focus must be placed on measuring service and end-user outcomes to improve the rigor and quality of such investigations, with well-powered randomized controlled trials being best placed to answer questions regarding efficacy and cost-effectiveness.

In summary, my systematic review, and my pilot task-shifting interventions in the South African context indicate that task shifting interventions such as these are acceptable and feasible, offering a promising solution to addressing the under-resourcing of mental health care. However, interventions should ideally be tailored to the specific communities they target, taking into account specific individual, community, technological, and sociodemographic factors. Future training interventions should provide more detailed descriptions of programme components and focus on measuring patient outcomes, while all task shifting interventions may benefit from incorporating an evaluation of cost-effectiveness. Task shifting presents a viable and accessible opportunity for creative innovation and as we work towards achieving mental health for all.

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I was granted full access to UCT's physical and online library resources, with expert consultant support for ethical and statistical advice. Office space was provided at UCT for the duration of the conduct of this PhD.

## List of abbreviations

Abbreviation	Full term
ACT	Assertive Community Treatment
AIDS	Acquired Immunodeficiency Syndrome
AFFIRM	Africa Focus on Intervention Research for Mental health
ARV	Antiretroviral therapy
CAMI	Community Attitudes Towards the Mentally Ill Scale
CAN	Camberwell Assessment of Needs Scale
CGI	Clinical Global Impressions
CHC	Community Health Centre
CHW	Community health worker
CIDI	Composite International Diagnostic Interview
CMD	Common mental disorders
DALY	Disability-Adjusted Life Year
DCM	Depression Care Manager
DSM	Diagnostic and Statistical Manual
GAD	Generalized Anxiety Disorder
GAD-7	Generalized Anxiety Disorder 7-item Scale
GAF	Global Assessment of Function Scale
HIV	Human Immunodeficiency Virus
HLOE	Highest Level of Education
ICD	International Statistical Classification of Diseases and Related Health Problems
INDEPTH-Uganda	INtegration of DEpression Treatment into HIV Care in Uganda
IPT	Interpersonal therapy
IQR	Interquartile range
LHW	Lay health worker
LMIC	Low- and middle-income countries

<b>Abbreviation</b>	<b>Full term</b>
LOCF	Last observation carried forward
M-health	Mobile Health
MAKS	Mental Health Knowledge Schedule
MAR	Missing at random
MARS	Medication Adherence Rating Scale
MBC	Measurement-based care
mhGAP	Mental health Gap Action Programme
mhGAP-IG	Mental health Gap Action Programme Intervention Guide
MHNCCS	Mental Health Nursing Clinical Confidence Scale
MHSU	Mental Health Service User
MICE	Multiple imputation with chained equations
MINI	Mini-International Neuropsychiatric Interview
NCD(s)	Non-communicable disease(s)
NET	Narrative exposure therapy
NGO	Non-governmental organization
PANSS:	Positive and Negative Syndrome Scale
PDS	Posttraumatic Stress Diagnostic Scale
PEPFAR	United States President's Emergency Plan for AIDS Relief
PHQ-2	Patient Health Questionnaire-2 item
PHQ-9	Patient Health Questionnaire-9 item
PRIME	PRogramme for Improving Mental Health CarE
PTSD	Post-Traumatic Stress Disorder
SASH	The South African Stress and Health Study
SCID-1	Structured Clinical Interview for DSM-IV-TR Axis I Disorders
SMI	Severe/Serious Mental Illness
SRQ	Self-Reporting Questionnaire

<b>Abbreviation</b>	<b>Full term</b>
TAU	Treatment as usual
TB	Tuberculosis
TC	Trauma counselling
UCT	University of Cape Town
USAID	U.S. Agency for International Development
WCDoh	Western Cape Department of Health
WHO	World Health Organization
YLD	Years Lost due to Disability
YLL	Years of Life Lost



## Glossary of terms

Term	Definition
Common mental disorders	Mental disorders which can be classified as either depressive disorders or anxiety disorders (World Health Organization, 2017a).
Community Health Worker	“Community based workers that help individuals and groups in their own communities to access health and social services, and educate community members about various health issues” (U Lehmann & Sanders, 2007)
Disability-Adjusted Life Year	The sum of the years of Life Lost and the Years Lost due to Disability (WHO, 2014)
Efficacy	The power to produce an effect
Effectiveness	The degree to which an intervention achieves the desired outcome
Feasibility	Able to be carried out successfully
High income countries	Countries that have economies with a gross national income per capita of \$12,236 or more. (The World Bank, 2017b)
Low income countries	Countries that have economies with a gross national income per capita, calculated using the World Bank Atlas method, of \$1,005 or less in 2016 (The World Bank, 2017b).
Lower middle-income countries	Countries that have economies with a gross national income per capita between \$1,006 and \$3,995 (The World Bank, 2017b)
Mental Health Service User	“a person receiving care, treatment and rehabilitation services or using a health service at a health establishment aimed at enhancing the mental health status of a user...” (South African Government, 2002)
Non-communicable diseases	A medical condition that is not due to an infectious agent, and cannot be transmitted between individuals, generally having a prolonged course without the prospect of complete cure (World Health Organization, 2014).
Severe Mental Illness	A mental illness of long duration, diagnosed according to the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013), which results in serious impairment in a number of domains of function (Schinnar, Rothbard, Kanter, & Jung, 1990).
Sub-Saharan Africa	The portion of the African continent that is situated south of the Sahara Desert.
Task Sharing	A definition of task shifting which highlights the continued involvement of specialist care providers in the delivery of care in the context of task shifting (Hanlon et al., 2016).

Term	Definition
Task Shifting	The delivery of health services by non-specialist workers who provide evidence-based interventions, with training, support and supervision (World Health Organization, 2007).
Treatment gap	The absolute difference between the true prevalence of a disorder and the proportion of treated individuals affected by the disorder (Patel, 2009).
Upper middle-income countries	Countries that have economies with a gross national income per capita between \$3,956 and \$12,235 (The World Bank, 2017b)
Years Lost due to Disability	Duration of disability (“non-fatal components of disease burden”) as a consequence of a specified condition. (WHO, 2014)
Years of Life Lost	Premature mortality (“fatal components of the disease burden”) as a consequence of a specified condition. (WHO, 2014)

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# **Preface**

## **Context**

Mental and substance use disorders cause significant disability worldwide. Mental health service resources are severely lacking, especially in low and middle-income countries. Task shifting has the potential to address this resource shortage. This PhD appraises current evidence for task-shifting interventions delivered by non-specialist workers for mental illness in low- and middle-income countries and pilots two levels of task shifting interventions in Cape Town, South Africa, to examine their feasibility in our context. I sought to identify and discuss barriers to the implementation of such interventions and make recommendations for future work. The list of publications associated with this PhD is presented below.

My hypothesis is that mental health interventions delivered by non-specialists are acceptable and feasible in Cape Town, and mental health training will result in improved knowledge, skills, confidence and attitudes in community health workers.”

## **Chapters**

Chapter 1 presents the background, context and rationale for the investigations which follow. Key concepts are described and clarified, and gaps in the literature pointed out, followed by a description of the research objectives of this PhD and an outline of the methods used in investigation.

Chapter 2 presents the processes and findings of a systemic review of interventions delivered by non-specialist health workers for mental illness in Sub-Saharan Africa.

Chapter 3 outlines the methods and findings of a pilot randomized controlled trial which investigated the acceptability and feasibility of a treatment-partner intervention with psychoeducation and mobile health components aimed at improving treatment adherence amongst adults with severe mental illness.

In Chapter 4 I present the processes and findings of the development and piloting of a structured mental health-training programme for community health workers through the use of a quasi-experimental design.

Chapter 5 summarizes the findings of the investigations I have conducted. I then discuss some of the factors which have impacted on the conduct and findings of the investigations, and present implications for future work in this field.

**Table 0-1 Chapters outline**

Chapter	Contents
1	Background and context
2	Systematic review of non-specialist care for mental illness in Sub-Saharan Africa
3	Randomized controlled trial of treatment partner and mobile health intervention
4	Mental health training for community health workers in Cape Town
5	Discussion and implications

## Publications associated with this PhD

Publication title	Authors	My role	Publication Status	Associated Chapter
Using a treatment partner and text messaging to improve adherence to psychotropic medication: A qualitative formative study of service users and caregivers in Cape Town, South Africa	Sumaya Mall <sup>1</sup> Goodman Sibeko <sup>1</sup> Henk Temmingh <sup>1</sup> Dan J Stein <sup>1</sup> Peter D Milligan <sup>1</sup> Crick Lund <sup>1,2</sup>	<ul style="list-style-type: none"> <li>• Study design</li> <li>• Questionnaire Design</li> <li>• Subject recruitment</li> <li>• Conduct of focus groups and in-depth interviews</li> <li>• Data analysis and interpretation</li> <li>• Preparation of manuscript</li> </ul>	Published:  African Journal of Psychiatry 2013 vol: 16 (5)  DOI: 10.4314/ajpsy.v16i5.49	Chapter 3
Caregiving for mental health service users: A study exploring the perceptions of mental health service users and their caregivers in Cape Town, South Africa	Goodman Sibeko <sup>1</sup> Peter D Milligan <sup>1</sup> Henk Temmingh <sup>1</sup> Crick Lund <sup>1,2</sup> Dan J Stein <sup>1</sup> Sumaya Mall <sup>1</sup>	<ul style="list-style-type: none"> <li>• Study design</li> <li>• Questionnaire Design</li> <li>• Participant contact and scheduling</li> <li>• Conduct of clinical outcome scales</li> <li>• Conduct of qualitative interviews</li> <li>• Data analysis and interpretation</li> <li>• Lead preparation and submission of manuscript</li> </ul>	Published:  International Journal of Social Psychiatry 2016 vol: 62 (6) pp: 512-521  DOI: 10.1177/0020764016651458	Chapter 3
Improving adherence in mental health service users with severe mental illness in South Africa: A pilot randomized controlled trial of a treatment partner and text message intervention vs. treatment as usual	Goodman Sibeko <sup>1</sup> Henk Temmingh <sup>1</sup> Sumaya Mall <sup>1</sup> Peter Williams-Ashman <sup>1</sup> Graham Thornicroft <sup>2</sup> Ezra Susser <sup>3</sup> Crick Lund <sup>1,2</sup> Dan J Stein <sup>1</sup> Peter D Milligan <sup>1</sup>	<ul style="list-style-type: none"> <li>• Study design</li> <li>• Intervention development: treatment partner contract, psychoeducation guide, mobile health platform design and testing</li> <li>• Questionnaire Design</li> <li>• Participant identification, screening and enrolment</li> <li>• Conduct of focus groups and in-depth interviews</li> <li>• Data interpretation</li> <li>• Preparation of manuscript</li> </ul>	Published:  BMC Research Notes (2017) 10:584  DOI: 10.1186/s13104-017-2915-z	Chapter 3
Mental Health Training for Community Health Workers in The Western Cape (Training Manual)	Goodman Sibeko <sup>1</sup>	<ul style="list-style-type: none"> <li>• Conceptualized, developed and published this training manual</li> </ul>	Published:  OpenUCT  <a href="http://hdl.handle.net/11427/22850">http://hdl.handle.net/11427/22850</a>  DOI: 10.13140/RG.2.2.26782.23367	

Publication title	Authors	My role	Publication Status	Associated Chapter
Piloting a mental health training programme for community health workers in Cape Town, Western Cape, an exploration of changes in knowledge, confidence and attitudes	Goodman Sibeko <sup>1</sup> Peter D Milligan <sup>1</sup> Marinda Roelofse <sup>4</sup> Lezel Molefe <sup>5</sup> Deborah Jonker <sup>1</sup> Jonathan Ipser <sup>1</sup> Crick Lund <sup>1,2</sup> Dan J Stein <sup>1</sup>	<ul style="list-style-type: none"> <li>• Study design</li> <li>• Ethics submissions</li> <li>• Health impact assessment submissions</li> <li>• Management of budget</li> <li>• Intervention development: Training manual, study site selections</li> <li>• Stakeholder engagement</li> <li>• Conduct of initial piloting</li> <li>• Direct supervision of training delivery and data collection</li> <li>• Data entry, analysis and interpretation</li> <li>• Manuscript preparation</li> </ul>	Manuscript accepted for publication in BMC Psychiatry	Chapter 4
Systematic review of mental health interventions delivered by non-specialist workers in Sub-Saharan Africa	Goodman Sibeko <sup>1</sup> Taryn Amos <sup>1</sup> Katherine Sorsdahl <sup>1</sup> Peter D Milligan <sup>1</sup> Dan J Stein <sup>1</sup> Crick Lund <sup>1,2</sup>	<ul style="list-style-type: none"> <li>• Study design and initiation</li> <li>• Trial identification</li> <li>• Data extraction</li> <li>• Risk of Bias assessments</li> <li>• Preparation of manuscript</li> </ul>	Manuscript currently under co-author review	Chapter 2

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# **Chapter 1 Background and context**

This chapter provides the background and context for the investigations conducted in this PhD. The local and worldwide burden of mental illness is described. This is followed by a discussion of treatment non-adherence amongst mental health service users, and the scarcity of available mental health resources to address these issues. There is then an introduction to task shifting and mobile health as potential solutions to this skills and resource shortage.

## **1.1 The burden of mental illness locally and worldwide**

Non-communicable diseases (NCD) have shown a 4-fold increase in burden in the years since the political transition in South Africa, most prominently amongst the urban poor (Mayosi et al., 2009). Worldwide, non-communicable diseases result in more early deaths (Under age 70) than the sum of other disorders, while acting as barriers to development and poverty alleviation (World Health Organization, 2014). Mental and substance use disorders specifically contribute significantly to the global burden of disease, accounting for 21.2% of years lived with disability (YLD) (Vos et al., 2015). The South African Stress and Health Study (SASH) conducted in 2009 found a lifetime prevalence of 30.3% for any psychiatric disorder with a lifetime risk of 47.5% for developing a psychiatric disorder (Herman et al., 2009). The Western Cape had the highest 12-month and lifetime (42%) prevalence rates in the country. While the SASH study found that anxiety, substance use and mood disorders were most prevalent in South Africa, Schizophrenia is known to be particularly disabling, affecting an estimated of 16.7 million individuals worldwide (Shakespeare & Officer, 2011). Schizophrenia falls into a group of mental illnesses defined as severe mental illness (SMI), which refers to a mental illness of long duration, diagnosed according to the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013), which results in serious impairment in a number of domains of function (Schinnar, Rothbard, Kanter, & Jung, 1990).

Families of people with SMI, while often being more tolerant to their mentally ill family member than the general public, often face multiple challenges and additional responsibilities (Nyati & Sebit, 2002). The sex of the mentally ill individual has been noted to mediate the extent of burden, with families of male schizophrenia sufferers experiencing more disruption than those of female sufferers (Awad & Voruganti, 2008). Symptom severity is associated with increased burden regardless of sex. Ironically, one study investigating the impact of insight on parental burden amongst parents of people with SMI found that an increase in parental insight only appears to worsen this burden as a consequence of self-stigma in the parents themselves (Hasson-Ohayon, Levy, Kravetz, Vollanski-Narkis, & Roe, 2011). This may be related to the shame, guilt, self-blame, and embarrassment that may be experienced by some parents (Awad & Voruganti, 2008).

It is well established that with prompt and appropriate intervention, this burden could be alleviated (Awad & Voruganti, 2008). In spite of this, much of the evidence documenting positive outcomes for family interventions for sufferers of severe mental illness remain unused and are not routinely integrated into management plans.

## **1.2 Non-adherence to treatment**

In spite of this disability burden, poor adherence to antipsychotic medication remains a significant challenge in the treatment of SMI, with non-adherence rates estimated at about 50% for prescribed antipsychotic medication (Liu-Seifert, Adams, & Kinon, 2005). Discontinuation of antipsychotic treatment, even after a single episode, is associated with high rates of relapse and early readmission rates, resulting in increased morbidity, decreased quality of life and increased demand on acute hospital services (Emsley, Chiliza, Asmal, & Harvey, 2013; Liu-Seifert et al., 2005; OECD, 2014), and early readmission (within the first three months following discharge is common (Heslin, Kevin C.; Weiss, 2015), with rates as high as 42.5% (Lin et al., 2006). Readmission rates of 15% at 90 days post discharge have been reported (Tulloch, David, & Thornicroft, 2016). A likely precipitant for psychotic relapse necessitating readmission is treatment non-adherence (Nose,

Barbui, & Tansella, 2003). Thus, there is significant interest in developing contextually appropriate interventions to improve medication adherence in individuals with psychotic disorders (Haynes, Ackloo, Sahota, McDonald, & Yao, 2008; Nose et al., 2003).

### **1.3 Resources for mental health**

Mental health services are comparatively under-resourced globally, with 0.9 psychiatrists per 100,000 population globally (World Health Organization, 2015a). Low and middle-income countries (LMIC) have a particular shortage of financial and human resources, with 0.1 psychiatrists per 100,000 population for low income countries, 0.4 for lower middle-income countries, and 1.2 for upper-middle income countries, compared to 6.6 for high income countries. South Africa, classed as upper middle income by the World Bank (The World Bank, 2017a), has 0.39 psychiatrists per 100,000 population (World Health Organization, 2017b). Socioeconomically deprived populations in low and lower-middle income countries like South Africa have the most pressing need for mental health care but are least likely to have access to it, as a result of the large treatment gap (Saxena, Thornicroft, Knapp, & Whiteford, 2007). The treatment gap is the absolute difference between the true prevalence of a disorder and the proportion of treated individuals affected by the disorder (Patel, 2009).

Availability and approach to mental health service delivery varies depending on the region's socioeconomic status (World Health Organization, 2015a). There is however consensus that a "balanced care" model, combining community and hospital-based care is ideal (Thornicroft & Tansella, 2004). The mechanisms of mental illness are complex, and this is reflected in the varied approaches to intervention research and service delivery (Stein, 2014). Better resourced countries have tended to combine centralized care with comprehensive community-based follow up and rehabilitation, while worse-off countries tend to focus on psychiatric hospitals (World Health Organization, 2015a). This is reflected in the spending by high income countries, of 58.73 USD per capita on mental health, fairly evenly split between inpatient and outpatient services, compared to

the 1.53 USD spent by lower middle income countries, of which 80% is earmarked for mental hospitals (World Health Organization, 2015a). Medium-resourced settings may go further by providing community-based support follow-up outpatient care at community health centres (CHCs).

In South Africa, Lund et al found that there was a total of 48 psychiatric beds per 100 000 population, which was higher than the world and African mean ratios but lower than that of European countries, with most of this located within more densely populated urban areas and earmarked for medium and long-term care (Lund, Flisher, Porteus, & Lee, 2002). This limitation emphasizes the need to develop and provide comprehensive mental health care that is responsive, community-based and integrated with primary health care, as proposed by The Mental Health Action Plan 2013-2020 (World Health Organization, 2013). The Mental Health Policy Framework and Strategic Plan 2013-2020, which was adopted in July 2013 therefore focuses on decentralizing mental health care through reinforcement and re-engineering of district and primary health services, amongst other structural recommendations (National Department of Health South Africa, 2009). With the current resource shortage, and this move towards integrated decentralized care, there is a need to reorganize resources such that acute services are better equipped to provide such services. To this end, there are some multinational initiatives engaged in generating an evidence base for the development and implementation of scaled-up integrated packages of care for mental health. One such initiative is the Programme for Improving Mental Health Care (PRIME), a United Kingdom-funded consortium of researchers and health ministries which focuses on integration in the context of primary and maternal health care in Ethiopia, India, Nepal, South Africa, and Uganda (Aims and Objectives of PRIME: Pg. 2) (Lund et al., 2012).

## **1.4 Task shifting**

Evidence generated by programmes like PRIME will be important steps towards heeding the call for innovation in mental health care delivery, with a particular focus on approaches that employ task shifting (Patel, 2009). Culturally appropriate task shifting approaches may play an important

role in addressing the treatment gap in LMIC (Patel, 2009; Inge Petersen, Lund, & Stein, 2011a; Sorsdahl, Stein, & Lund, 2012). Task shifting refers to the delivery of health services by non-specialist workers who provide evidence-based interventions, with training, support and supervision (World Health Organization, 2007). The terms task shifting and task sharing are often used interchangeably, however some authors use the latter to highlight the continued involvement of specialist care providers in the delivery of care in the context of task shifting (Hanlon et al., 2016). There is a growing evidence base of efficacy and effectiveness trials demonstrating that such innovation is feasible, efficacious, and effective (van Ginneken et al., 2013a).

Four types of task shifting have been outlined (World Health Organization, 2007). In type 1 task shifting, diagnostic and prescribing privileges are delegated from doctors and specialists to non-physician clinicians such as nurses and clinical officers. Type 2 task shifting entails nurses/midwives taking on clinician roles previously reserved for medical officers or clinical officers. In type 3 task shifting nurses' and midwives' tasks are delegated to nursing assistants or nursing aides; or community health workers (CHWs). Type 4 task shifting involves the delegation of tasks from nurses/CHWs to expert patients, peers or patients' relatives (caregivers).

By using task shifting processes to reorganize the workforce more efficient use of human resources is possible (World Health Organization, 2007). For example, task shifting has been found to be an effective strategy for addressing shortages of human resources for health in HIV treatment and care (Callaghan, Ford, & Schneider, 2010). They have been noted to neither decrease quality of care nor increase adverse events, while potentially increasing treatment follow up rates (Tamara Kredo, Adeniyi, Bateganya, & Pienaar, 2014).

There has been particular interest in the potential role of CHWs in mental health care delivery in primary care settings (Bhana, Petersen, Baillie, Flisher, & The MHaPP Research Programme Consor, 2010; Kakuma et al., 2011; Patel, 2009). A range of other human resources, including non-specialist health professionals; lay workers; affected individuals; and caregivers, if

provided with training and appropriate supervision by mental health specialists, have the potential to detect, diagnose, treat, and monitor individuals with mental disorders and reduce caregiver burden (Kakuma et al., 2011).

Current studies emphasize, however, that there are barriers to the use of task shifting. In some cases policy makers have embraced the concept of task shifting, while healthcare workers remain apprehensive about their value (Dambisya & Matinhure, 2012). Absence of clear policy and guidelines have been associated with misconceptions about the meaning and intentions of task shifting, while factors favouring task shifting have included evidence of previously successful task shifting interventions, proper referral channels and the need for services in a scarce skills setting (Dambisya & Matinhure, 2012).

#### **1.4.1 Community health workers**

##### ***Defining community health workers***

CHWs are “community based workers that help individuals and groups in their own communities to access health and social services, and educate community members about various health issues” (World Health Organization, 2015b). A review exploring the trends in the definitions of CHWs worldwide found that CHWs tend to have an in-depth understanding of their community’s language, and cultural beliefs and practices and language, delivering health care that is culturally appropriate (Olaniran, Smith, Unkels, Bar-Zeev, & van den Broek, 2017). CHWs require shorter, less specialized training than professional health care workers and need not be part of the organization of a health system but should be supported by it (Olaniran et al., 2017; World Health Organization, 2010). CHWs may further be classified as lay health workers who have little or no formal education but some informal training; level 1 paraprofessionals who have some secondary education and informal training; and level 2 paraprofessionals who have some secondary education but have more extensive formal training (Olaniran et al., 2017).

CHWs managed by non-governmental organizations (NGOs) have a long and colourful history in South African (Clarke, Dick, & Lewin, 2008). Initially primarily led by white doctors and nurses in an effort to provide the underserved poor black population, CHWs inevitably became entangled in the socio-political landscape of the apartheid era (van Ginneken, Lewin, & Berridge, 2010). As the country transitioned out of apartheid the incoming government viewed the health care delivery by CHWs as being potentially inferior in quality (Clarke et al., 2008). As a result of disinvestment by national government it then fell upon provinces to manage the use of partially government-funded CHW programmes in the delivery of community-based care. In response to the HIV epidemic, the 2008 reauthorization of the United States President's Emergency Plan for AIDS Relief (PEPFAR) seeks to strengthen health systems and the capacity of the health workforce with integration of HIV and AIDS programmes into health systems (USAID, 2017). In South Africa the U.S. Agency for International Development (USAID), an implementing agency for PEPFAR, has invested in the development of training curricula to increase the number of CHW in the health care system. This has fuelled a proliferation of CHW, particularly funded through NGOs which have been contracted by government to employ and manage them, thus forming a link between community health, primary health care and district health resources (Schneider & Lehmann, 2016). This represents a reversal of the previous disengagement by government, the revised Community Care Worker Management Policy Framework 2009 seeks to provide guidelines on the management and legislative protection of CHWs while clarifying departmental and programme accountability in ensuring the quality of the service delivered (National Department of Health South Africa, 2009).

### ***The impact of community health workers***

In high-income countries CHWs mainly offer health promotion, counselling and support (Glenton et al., 2013). In LMIC, CHWs offer similar services, often with the additional responsibility of distributing treatment, as well as diagnosing and treating uncomplicated cases, while referring those requiring specialized care. This cadre of health worker may thus play an important role in

identifying targets for treatment as well as improving health outcomes. Such interventions may result in reduced costs for patients, particularly when it concerns travel costs to medical facilities for follow up or treatment where task shifting brings care and support closer to where the patients live (T Kredo, McCaul, & Volmink, 2015; Vigod et al., 2013).

In malaria research, interventions involving CHWs and family members have improved appropriate access to malaria treatment (Okwundu, Nagpal, Musekiwa, & Sinclair, 2013). In the area of community-based intervention packages for maternal and child health, there has been a noted improvement in care-related outcomes for low- and middle- income countries (Lassi & Bhutta, 2015). There has been a demonstrated reduction in morbidity for women as well as mortality and morbidity for infants.

Barriers and facilitators impacting of CHW programmes aimed at improving access to services have been linked to programme acceptability, appropriateness and credibility; as well as health system constraints (Glenton et al., 2013). The familiarity that CHWs have with communities is described as a programme strength, however the drawbacks of this familiarity need to be taken into account so as to maximize benefit. Over and above the positive appraisal of such interventions as relevant by service users, the up skilling of CHWs, and the improved penetration of primary health care services, the involvement and support of community and the health system are important facilitators.

### ***Mental health training for community health workers***

While it is early-days in the literature, it is heartening to see the promising evidence for the effectiveness of CHWs. In order to deliver the community based mental health care services, appropriate training has to be made available. The evidence for the effectiveness of mental health training programmes for CHWs remains very limited. It is therefore unclear what type of mental health training programme would be most effective in our local setting, and whether such training



would result in adequate improvement in knowledge, skill, confidence and attitudes for CHWs expected to deliver mental health care.

#### **1.4.2 The current state of evidence for task shifting in mental health care**

There is some evidence that types 3 and 4 task shifting interventions may be efficacious in the delivery of mental health care (Neuner et al., 2008; Patel et al., 2010; Rahman, Malik, Sikander, Roberts, & Creed, 2008; van Ginneken et al., 2013a). Trials have investigated task shifting for depressive illness; depressive illness with or without comorbid anxiety; post-traumatic stress disorder; dementia and substance use disorders. The evidence for these findings is noted to be mostly of low or very low quality, with some areas, such as intervention adverse effects and outcomes in children, lacking any evidence at all (van Ginneken et al., 2013a). A recent review of task shifting interventions employing psychosocial interventions has demonstrated promising outcomes in reducing burden related to common mental disorders (CMD) (Singla et al., 2017). It is unclear how acceptable and feasible these kinds of task shifting interventions, with a focus on SMI, would be in our local context. It also remains to be established what approach would be best to measure efficacy outcomes in our populations.

### **1.5 Mobile health, context and potential**

Mobile health (m-health), defined as medical and public health practice supported by mobile devices, such as mobile phones, is gaining popularity with the increased penetration of cellular technology worldwide (WHO, 2011). There is growing evidence for the effectiveness of m-health approaches in maternal and child health and in chronic illness in LMIC (Balakrishnan et al., 2016; Beratarrechea et al., 2014; Catalani, 2013; Tamrat & Kachnowski, 2012). A high penetration of mobile phone use has been noted, specifically in developing countries, with 89% of South Africans owning a mobile phone (Pew Research Center, 2015; van Heerden, Tomlinson, & Swartz, 2012). Unsurprisingly therefore, text messages remain the predominant mode of m-health in interventions

in Africa (Forrest et al., 2015). In HIV/AIDS research, text message interventions have improved appointment adherence and communication between health care workers (Mukund Bahadur & Murray, 2010).

Very little has been done to investigate the use of m-health in interventions aimed at supporting adherence for severe mental illness, with current evidence being inconclusive (Kauppi et al., 2014). Even less is known about the concurrent use of m-health with the task shifting approach. Further, little is known about whether CHW training programmes focussed on mental health result in improved knowledge, skill, confidence and a change in attitudes towards mental illness.

## **1.6 Research objectives and methods**

This PhD begins with a systematic review of interventions by non-specialist workers for mental illness in Sub-Saharan Africa, followed by the piloting of specific task shifting interventions for mental illness in Cape Town, South Africa. The first task shifting intervention was tested in a pilot randomized controlled trial (RCT) investigating the acceptability and feasibility of a treatment partner task-shifting intervention with monthly text message clinic appointment reminders aimed at improving adherence for people with severe mental illness. I have then developed and piloted a training programme for CHWs in the Western Cape and evaluated the impact of the programme on CHW knowledge, confidence and attitudes and suggested an approach for future work investigating service and service user outcomes. The acceptability and feasibility of the training programme were also evaluated. The specific methods are described within the text of each chapter. Investigation procedures and findings are presented according to recognized guidelines in order to ensure reporting quality, namely The PRISMA Statement for the systematic review; the CONSORT Statement for the RCT; and the STROBE statement for the CHW intervention (Liberati et al., 2009; Schulz, Altman, Moher, & Group, 2010; Vandenbroucke et al., 2014).

## **Chapter 2 Systematic review of non-specialized care for mental illness in Sub-Saharan Africa**

In order to characterise the current evidence for task shifting interventions in Sub-Saharan Africa, this chapter presents a narrative report of the procedures and findings of a systematic review of care provided by non-specialized health workers for mental illness in Sub-Saharan Africa.

### **2.1 Background**

Countries in Sub-Saharan Africa overwhelmingly fall into the category of low and middle-income countries (LMIC) (World Bank, 2004; World Health Organization, 2017). These countries face a particular challenge, given the inequitable distribution of available human and other resources for mental health care and treatment (World Health Organization, 2015a). Sub-Saharan African countries have 0.1 psychiatrists per 100,000 population. The total mental health workforce, consisting of doctors with mental health training, nurses, psychologists and social workers, is equally lacking, resulting in a treatment gap (Patel, 2009).

Interventions delivered by non-specialist health workers may play an important role in addressing the treatment gap in Sub-Saharan Africa by reorganizing the health workforce to make more efficient use of human resources (Patel, 2009; Inge Petersen, Lund, & Stein, 2011b; Sorsdahl, Stein, & Lund, 2012; WHO, 2008). By using task-shifting processes to reorganize the workforce more efficient use of human resources is possible (World Health Organization, 2007b). For example, task shifting has been found to be an effective strategy for addressing shortages of human resources for health in HIV treatment and care (Callaghan, Ford, & Schneider, 2010). Evidence suggests that the care delivered by nurses and community health workers results in improved rates of follow-up while being not inferior to that delivered by doctors (Tamara Kredo, Adeniyi, Bateganya, & Pienaar, 2014). There has been particular interest in the potential role of community health workers in delivering mental health care services in primary care settings (Bhana, Petersen, Baillie, Flisher, & The Mhapp Research Programme, 2010; Chibanda et al., 2011; Kakuma et al., 2011; Patel, 2009). Potential

benefits of this integration of mental health care into primary health care include improvements in access to care, and health outcomes (Funk, Saraceno, Drew, & Faydi, 2008). Initiatives such as the PRogramme for Improving Mental health carE (PRIME) and the Africa Focus on Intervention Research for Mental health (AFFIRM) aim to generate evidence for the implementation of this approach through task sharing (Davies & Lund, 2017).

A range of other human resources, including non-specialist health professionals, lay workers, affected individuals, and caregivers, if provided with training and appropriate supervision by mental health specialists, have the potential to detect, diagnose, treat, and monitor individuals with mental disorders and reduce caregiver burden. (Kakuma et al., 2011)

Current studies emphasize, however, that there are barriers to the use of task shifting or task sharing interventions. For example, in some cases, while policy makers have embraced the concept of task shifting, healthcare workers remain apprehensive about its value (Dambisya & Matinhure, 2012). Absence of clear policy and guidelines have been associated with misconceptions on the meaning and intentions of task shifting, while factors favouring task shifting included evidence of previously successful task shifting interventions, proper referral channels and the need for services in a scarce skill setting. Clear policy, defining roles and responsibilities, is essential for the successful implementation of such interventions while ensuring the protection of MHSU (Funk, Drew, José Miguel Caldas De Almeida, Saraceno., Xiangdong Wang, & Taylor, 2005).

Given increased attention to the mental health treatment gap and the potential role of task shifting, there is a need for rigorous research on the efficacy of such interventions. A recent systematic review characterized the evidence for the use of non-specialist health workers in addressing mental illness in LMIC (van Ginneken et al., 2013a). The authors concluded that these cadres represented a promising resource, particularly in the management of common mental disorders. A number of trials of interventions by non-specialist health workers have been

undertaken in Sub-Saharan Africa specifically. This systematic review intends to characterize the evidence for these particular interventions.

The PICO framework allows for the phrasing and answering of a clinical research question in a systematic review (da Costa Santos, de Mattos Pimenta, & Nobre, 2007), which entails the identification of the population of interest, the intervention of interest, and the outcome of interest. In line with this framework, this review investigated the following question: In adult patients with mental disorders as per ICD or DSM diagnostic criteria, how do interventions delivered by non-specialists in sub-Saharan Africa compare with treatment as usual in terms of acceptability and feasibility; treatment adherence, symptomatic relief and quality of life (Figure 2-1).

**Figure 2-1 PICO Framework for this review**

Component	Details
<i>Population</i>	Adult patients with mental disorder as per ICD or DSM
<i>Intervention</i>	Interventions delivered by non-specialists in sub-Saharan Africa
<i>Comparison</i>	Treatment as usual
<i>Outcome</i>	Acceptability, feasibility, treatment adherence, symptomatic relief, quality of life

## 2.2 Methods

### 2.2.1 Protocol and registration

The protocol for this review is registered on the International prospective register of systematic reviews PROSPERO (CRD42017065190). Registration preceded the start of review activities.

### 2.2.2 Study eligibility criteria

Included trials were of interventions a) delivered by non-specialist health workers for b) adult populations (18-65 years) with c) psychiatric disorders diagnosed in line with ICD or DSM

classification systems in d) Sub-Saharan Africa. No restriction was placed on the nature of the psychiatric disorder. Additionally, the language of the study report was not grounds for exclusion.

### **2.2.3 Information sources and search strategy**

Between 21 and 28 June 2017, the search for eligible studies published prior to 21 June 2017 was conducted by searching the Cochrane library, PsychInfo, and Medline databases using the terms “non specialized” OR “non specialist” OR “task shifting” OR “task sharing” OR caregiver OR “community health worker” OR “community care worker” OR “lay health worker” AND Intervention OR trial AND "mental illness" OR “psychiatric illness” OR schizophrenia OR psychosis OR "psychotic disorder" OR "bipolar mood disorder" OR “manic depression” OR depression OR “depressive illness” OR “anxiety” OR anxiety disorder” OR psychotic AND “Sub-Saharan Africa” OR “Africa”. The World Health Organization International Clinical Trials Registry was also searched using the terms Psychiatric illness OR Mental Illness OR Psychiatric disorder OR Mental disorder (Condition) AND Treatment OR Intervention OR Trial (Intervention), as was the Pan African Clinical Trials Registry using the search terms “Psychiatry” or “Mental Illness” as the area of interest and the key words “Intervention” and “Treatment”. The bibliographies of study reports for all eligible trials were scanned for additional studies.

This process was conducted in line with the PRISMA statement, which is composed of a 27-item checklist and a flow diagram (Moher D, Liberati A, Tetzlaff J, 2009), and provides guidance for the conduct and reporting of systematic reviews (Liberati et al., 2009).

### **2.2.4 Study selection and data collection**

Trials were assessed for eligibility based on the eligibility criteria, using the methodology prescribed in the *Cochrane Handbook* (Higgins & Green, 2011). Sampling, methodological and outcome data were extracted from each trial, and entered into a customized data extraction form

based on setting; study design; sample size; age and gender distribution; intervention; and continuous and dichotomous outcome variables. Of interest were the impact of interventions on treatment adherence; symptomatic relief and improvement in quality of life; as well as in the acceptability and feasibility of these interventions.

### **2.2.5 Risk of Bias Assessments**

Risk of bias data were extracted for all included trials. Randomized studies were assessed for quality of reporting based on guidelines from the Cochrane Collaboration Handbook for Systematic Reviews of Interventions (Higgins & Green, 2011). The following domains were considered: 1) Selection bias which may arise from random sequence generation and allocation concealment; 2) Reporting bias which may result from selective outcome reporting; 3) Performance bias which may arise from the extent to which participants and personnel have been blinded to the randomization condition; 4) Detection bias as measured by blinding in the assessment of outcomes; 5) Attrition bias as measured by the reporting of incomplete outcome data; and 6) Other sources of bias, which includes potential sources of bias not included in the other domains, such as that which might arise from the undue influence of a funder.

A description of what was reported to have happened in each study is presented, and the risk of bias judgements made for each study and across studies, based on three categories: low, unclear and high risk. Low risk of bias applies where bias is unlikely to seriously alter confidence in the results; unclear risk of bias applies where bias raises some doubt about the results and high risk of bias where bias seriously weakens confidence in the results.

The Risk of Bias In Non-randomised Studies - of Interventions (ROBINS-I) tool was used to assess the risk of bias of the non-randomized trials. The tool is based on the Cochrane Risk of Bias Tool and incorporates components of other tools such as the QUADAS 2 tool which is used to evaluate diagnostic accuracy in trials (Whiting et al., 2011). The following domains are considered:

1) Bias due to confounding; 2) Bias in selection of participants into the study; 3) Bias in classification of interventions; 4) Bias due to deviations from intended interventions; 5) Bias due to missing data; 6) Bias in measurement of outcomes; and 7) Bias in selection of the reported result.

The tool makes use of signalling questions in the risk assessment, the answers to which may be: a) Yes; b) Probably yes; c) Probably No; d) No; and e) No information. The weighting of the response depends on the signalling question, which response informs the logarithmic instruction for the next signalling question. Judgements of risk are then made at the end of each set of signalling questions with the following response options: a) Low risk of bias; b) Moderate risk of bias; c) Serious risk of bias; d) Critical risk of bias; and e) No information. The lower the risk of bias the more comparable a study is considered to a well-performed randomized controlled trial (RCT).

I and another review author (TA) assessed the risk of bias in selected studies. Any disagreements were discussed with a third review author (CL).

## **2.2.6 Synthesis of results**

A narrative synthesis of the included studies was conducted, describing the type of intervention tested, the study design used, the role of non-specialist health workers, as well as the findings of each study.

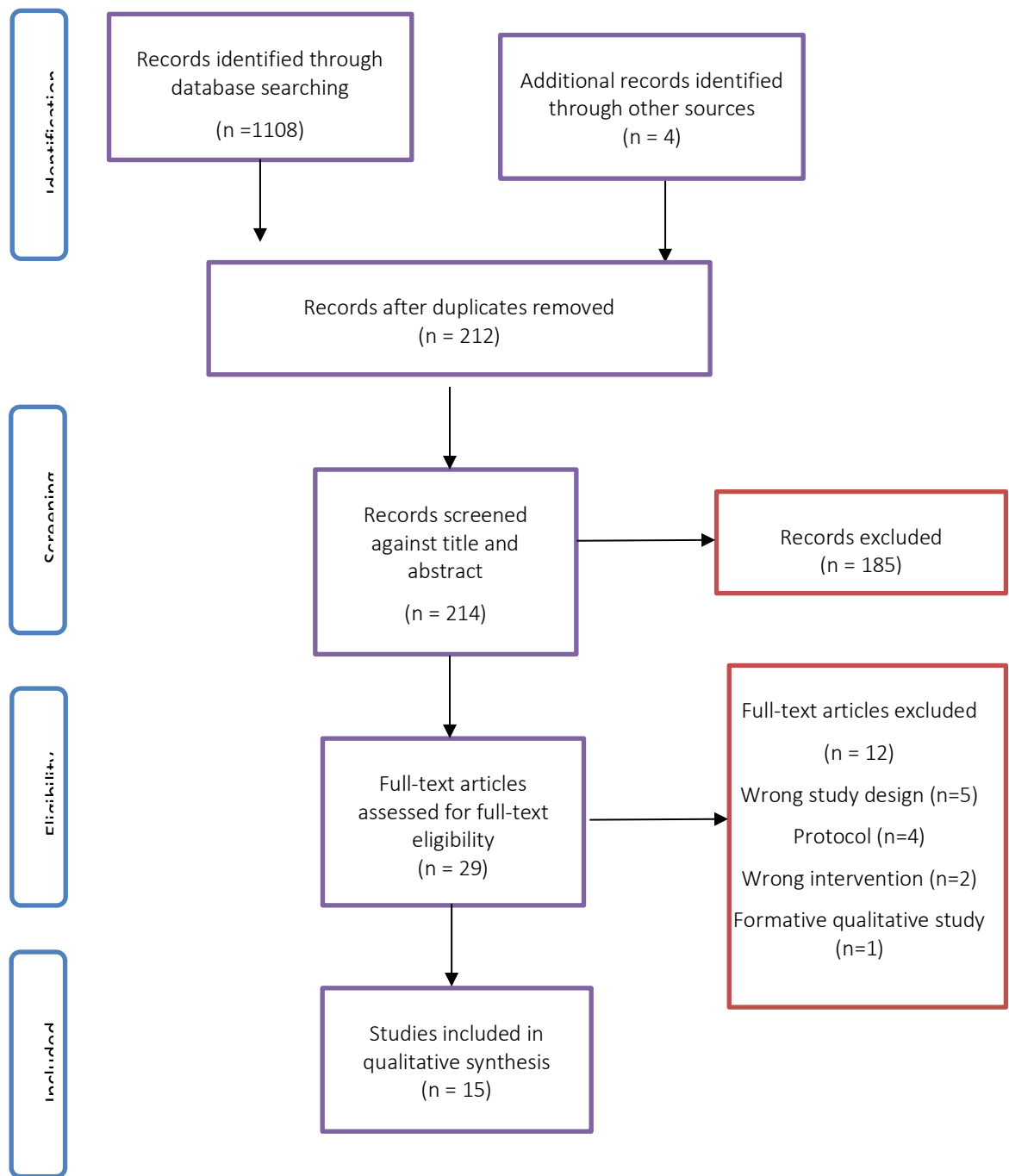
## **2.3 Results**

### **2.3.1 Study selection**

The PRISMA flow diagram for this review is presented below (Figure 2-2). The initial search yielded 1108 records, with an additional 4 records retrieved from the bibliographies of identified literature. After screening for eligibility and full-text review, fifteen studies met inclusion criteria and were included in this review. The characteristics of included and excluded studies are described below.



Figure 2-2 PRISMA Flow Diagram



### **2.3.2 Description of included studies**

Table 2-1 presents the characteristics of included studies. Interventions included psychotherapeutic interventions (Andersen et al., 2016; P Bolton et al., 2003; Chibanda et al., 2011a, 2016; Neuner et al., 2008; I Petersen, Hanass Hancock, Bhana, & Govender, 2014a; Inge Petersen, Lund, Bhana, & Flisher, 2012; Sorsdahl et al., 2015; Tomlinson, Rotheram-Borus, Scheffler, & le Roux, 2017), psychosocial interventions (Brooke-Sumner, Lund, Selohilwe, & Petersen, 2017; Musyimi, Mutiso, Ndeti, Henderson, & Bunders, 2017a; Scholte et al., 2011), and manualized care models (Adams, Almond, Ringo, Shangali, & Sikkema, 2012a; Musyimi et al., 2017a; Neuner et al., 2008; Pence, Gaynes, Atashili, O'Donnell K., et al., 2014; Wagner et al., 2016). Interventions focussed largely on common mental disorders, namely depression and post-traumatic stress disorder, with only 1 trial detailing the development of an intervention for severe mental illness (Brooke-Sumner et al., 2017). Participants were mostly female.

#### **2.3.2.1 Study procedures**

All included trials stated appropriate ethics clearance. I was however not able to access the study protocols of 9 of the 15 studies (Adams et al., 2012a; Paul Bolton et al., 2003; Brooke-Sumner et al., 2017; Musyimi, Mutiso, Ndeti, Henderson, & Bunders, 2017b; Neuner, Schauer, Klaschik, Karunakara, & Elbert, 2004; Pence, Gaynes, Atashili, O'Donnell K., et al., 2014).

While not all studies explicitly described their sampling approach, identified techniques varied between studies. Some trials made use of convenience sampling, accessing potential participants who were already in attendance at an HIV health treatment facility (Adams, Almond, Ringo, Shangali, & Sikkema, 2012b; Pence, Gaynes, Atashili, O'Donnell, et al., 2014; Sorsdahl et al., 2015). One trial accessed service users who were in attendance at the local traditional health practitioner (Musyimi et al., 2017b). Two trials approached potential participants in their homes (Neuner et al., 2008; Tomlinson et al., 2017), and one identified potential participants from the day's list of patients waiting to receive their ART medication refills (Andersen et al., 2016). Brooke-

Sumner identified potential participants through the review of clinic records after which community health workers then went into the community to recruit the participants from their homes (Brooke-Sumner et al., 2017). Bolton accessed community leaders and made use of their knowledge of the community to identify potential participants, who were then approached at home to be invited to participate in the study. Chibanda 2011 made use of advertising conducted by community health workers and via public notice boards, which meant that in addition to referral by health practitioners some of participants were self-referred (Chibanda et al., 2011a). Two trials made use of purposive sampling, where a mental health counsellor actively invited participants to participate in the study (I. Petersen, Bhana, & Baillie, 2012; I Petersen, Hanass Hancock, Bhana, & Govender, 2014b).

#### **2.3.2.2 Non-specialist workers**

##### ***Selection***

Two trials drew study staff from the clinical teams at the facilities acting as study sites. One of these chose a nurse and clinical officer identified by the director of the clinic at which the study was being conducted (Adams, Almond, Ringo, Shangali, & Sikkema, 2012a). Both had extensive training and experience in HIV but none in mental health. In the other trial this approach was chosen in a bid to select intervention staff that reflected the standard health care provider at the primary care facility (Andersen et al., 2016). One trial with a similar focus on sustainability, and following extensive stakeholder consultation, secured the involvement of auxiliary social workers with supervisors from their sectors (Brooke-Sumner, Lund, Selohilwe, & Petersen, 2017).

Other trials drew lay study staff from within the community being studied. Ten lay health workers were randomly selected to deliver the intervention in Zimbabwe, where this cadre of worker is seen as a reliable extension of the primary health care system (Chibanda et al., 2011a, 2016). They are generally literate females who have lived in their communities for a long period of time. Their roles include chronic medical adherence and health literacy support within their communities. In another trial, refugees with no prior medical, psychological or social services

training or experience were selected to be trained as lay counsellors for their own community (Neuner et al., 2008). Five female and 4 male lay counsellors with a mean age of 27 were selected and trained. The minimum requirements for acceptance to training were English and mother-tongue literacy, empathy and motivation. Three of the selected lay counsellors had lifetime PTSD, with two experiencing current PTSD. These individuals received Narrative Exposure Therapy (NET) from the trainers as part of their training. Tomlinson et al selected Mentor Mother CHWs referred by local leaders and stakeholders (Tomlinson, Rotheram-Borus, Scheffler, & le Roux, 2017). The mentor mothers had been observed during training and finally selected on the basis of punctuality, attentiveness, demonstrated problem-solving ability and good interpersonal skills.

Some trials opted for an approach that combined elements of the above approaches. Pence et al selected a local nurse with standard nursing training to be the Depression Care Manager (DCM) in a manualized care intervention (Pence, Gaynes, Atashili, O'Donnell, et al., 2014). She had 12 years of experience as a nurse/pharmacy attendant but had no prior training in mental health. Similarly, Scholte et al chose 8 local interviewers who were sociology students with no mental health experience to conduct interviews with participants, and local people to facilitate the intervention groups (Scholte et al., 2011). In Cape Town the 5 counsellors recruited to conduct the brief intervention originated from the local communities (Sorsdahl et al., 2015). They had a bachelors-level education or equivalent experience.

### ***Training and supervision***

Training focussed on the specific needs of each intervention. Adams et al cadres received training in research ethics as well as in-service training to provide them with the competence to detect and manage depression in the context of HIV (Adams, Almond, Ringo, Shangali, & Sikkema, 2012a). Training covered the recognition of features of depression and the principles of management of depression, which included recognition of new psychiatric concerns. This was followed by training in the study instruments and management algorithm. Supervision was

conducted weekly with a specialist psychiatrist, at which time PHQ-9 scores would be reviewed, as would standard HIV treatment regimens. The psychiatrist reviewed medication decisions made according the algorithm and made recommendations as appropriate to the DCM and clinician.

Brooke-Sumner et al trained 15 non-specialist workers, inclusive of auxiliary social workers and social workers from the Department of Social Development and the Mental Health Society; as well as supervisors from Department of Social Development (Brooke-Sumner, Lund, Selohilwe, & Petersen, 2017).

Chibanda et al trained 20 lay health workers over 8 days (Chibanda et al., 2011a, 2015). The training was conducted by two clinical psychologists, a general nurse with training in systemic counselling, and a specialist psychiatrist. Training included education on common mental disorders (CMD), “kufungisisa” (thinking too much), and focussed on identification of CMD with the use of the Shona Symptoms Questionnaire (SSQ). Trainees were taught ways to manage CMD with the use of uncomplicated psycho-education and problem-solving. Training further included pre-screening, and standard and emergency referral processes within the clinic. Supervision consisted of a daily peer-support group for the lay workers, which was facilitated by one of the lay workers who subsequently presented at a weekly group supervision for all the lay workers. This group supervision was conducted by a trained clinic staff nurse, with additional fortnightly supervision being provided by a clinical psychologist, and by a psychiatrist on a monthly basis.

Musyimi et al trained community health worker with no prior formal training, for two days on the administration of the Beck’s Depression Inventory (BDI) at baseline (0 weeks), 6 weeks and 12 weeks among patients seeking care from THPs. They received training on record keeping, defaulter-tracing and on the importance of follow-up (Musyimi, Mutiso, Ndeti, Henderson, & Bunders, 2017a).

The 6 week training of research assistants by Neuner et al focussed on quantitative data collection and interviewing techniques (Neuner et al., 2008). The lay counsellor trainees were

trained in general counselling skills as well as specific skills and techniques required for both intervention approaches. All trainees were educated in all approaches. Training was conducted by 5 post-doctoral- and doctoral-level staff. A senior expert counsellor who had developed the Trauma Counselling protocol facilitated that part of training. Trainee counsellors were closely supervised for both approaches before being allowed to work independently with clients. Ongoing case and individual supervision were then maintained on a weekly basis. The monitoring of treatment adherence was done through case discussions in supervision meetings, by the observation of treatment sessions, and by review of testimonies and treatment protocols.

Pence et al trained the DCM and HIV clinician in the diagnosis of depression, excluding diagnoses, and approaches to the treatment of depression with an emphasis on Measurement-Based Care (MBC) (Pence, Gaynes, Atashili, O'Donnell K., et al., 2014). The management of suicidality and medication side effects was also covered. Weekly teleconference supervision with a psychiatrist was arranged for the DCM. In this supervision, all visits and clinical decisions from the past week were discussed and reviewed, specifically focussing on key measures for each participant visit, namely severity of depression, severity of side effects, suicidality, and treatment plan.

In Petersen 2012, 30 CHWs split into two groups of 15, were trained over two 4-day workshops by a psychologist and trainee psychologists (I. Petersen, Bhana, & Baillie, 2012). Petersen 2014 adopted the same structure, where the first two days focused on micro-counselling skills as well as different ways to provide assistance, which included psycho-education, problem solving, positive thinking and the promotion of physical activity (I Petersen, Hanass Hancock, Bhana, & Govender, 2014a). The subsequent two days covered group-based sessions and built on areas addressed during the first two days. The lay counsellors received weekly supervision sessions with the clinical psychology trainees for the first two months and then monthly.

Peer counsellors in the Sorsdahl trial received 18 hours of training in Motivational Interviewing (MI) by a MI trainer (Sorsdahl et al., 2015). Proficiency was tested through role-play

and case examples. Three half-day booster training sessions were provided to reduce intervention drift and ensure that the MI fidelity. The counsellors also received 12 hours of training in Problem Solving Therapy (PST) with proficiency tested as above. Peer counsellors additionally received training in alcohol and substances of abuse and associated risks; the use of and scoring of the Alcohol, Smoking, and Substance Involvement Screening Test (ASSIST); ethics of research and importance of confidentiality and reporting of adverse events; the intervention protocol, and the process of referring patients for specialized care. Intervention fidelity was ensured through bi-weekly supervision and debriefing by a clinical social worker. Cases were reviewed in this session, with additional supervision being in the form of review of 50% of audiotaped sessions by the principal investigator. Corrective feedback was provided on the basis of this review.

Tomlinson et al trained Mentor Mothers over a 2-month period initially during the design of an evidence-based culturally appropriate intervention manual (Tomlinson, Rotheram-Borus, Scheffler, & le Roux, 2017). Forty women were accepted for training, and 13 finally enrolled as Mentor Mothers. Mentor Mothers worked 4 hours daily, attending home visits 4 days a week and supervision 1 day weekly. On 2 visits in a month, Mentor Mothers were accompanied by a supervisor on their home visits with the Mentor Mother. Mentor Mothers carried mobile phones loaded with a specific application which allowed for mobile monitoring and supervision. The application provided guidance on which pre- or postnatal session needs to be delivered after they entered the client's identifying information identifying just before entering a home for a visit. On exiting the home Mentor Mothers were prompted to select the core intervention topic, of a possible 8, discussed during the visit. The mobile application entry and exit survey time stamps were used to calculate visit duration. Supervisors reviewed this information and discussed it during the weekly supervision meetings. Points discussed included why certain topics were not covered, which may have been due to time constraints, other priorities and non-applicability. Further decision-making support was then provided.

Wagner et al started training by conducting an intensive one-day workshop with the clinic staff (Wagner et al., 2016). This training, conducted by the lead investigators and psychiatrists, attended by expert clients, nurses and clinical/medical officers, focused on the structure and goals of the study, and all components of the treatment model. Separate workshops were held for the clinics in the arm making use of the treatment protocol, and for those in the clinical acumen arm. Training consisted of lecture-type instruction, role-play, and breakout group discussions. Following the workshop, onsite training was conducted 1 day a week for 4-6 weeks, with study tools, including laminated copies of the PHQ-2 for the triage station, and PHQ-9/MINI for each nurse/prescribing clinician, along with a Depression Treatment Registry, and psychoeducation posters and flipcharts. This additional training was continued until both the supervisor and nurse were comfortable with the nurse's competency in implementing the protocol. Further training and mentorship in the form of sitting in on sessions and co-conducting assessments and decisions were conducted in this additional training, after which ongoing on-site supervision was conducted on a monthly basis. During this session, new and difficult or poorly-responsive cases were presented and their treatment plans discussed. Case and chart reviews were conducted with clinical notes from the Depression Registry. The supervisors then conducted a chart review for all patients who had been given antidepressant prescriptions. The charts of 10 randomly selected patients receiving depression monitoring were also reviewed. Chart review focussed on whether diagnosis, symptoms and side effect assessments had been appropriately performed. Chart review also assessed whether dosing decisions had been made appropriately performed, and whether the patient had in fact returned for follow-up visits. This monthly one-on-one supervision between the supervisor and each nurse, was complemented by additional group meetings with all involved clinic staff. Group staff meetings allowed for trouble-shooting of challenges as a team, to provide peer support through the sharing of experiences. The supervisor was available by phone at all times for any urgent consultations.

#### **2.3.2.3 Measures**



Table 2.1 presents the tools used as screening and outcomes measures in the included studies. The more commonly used screening measures were the Patient Health Questionnaire (PHQ) (Adams, Almond, Ringo, Shangali, & Sikkema, 2012a; Pence, Gaynes, Atashili, O'Donnell K., et al., 2014; Wagner et al., 2016), the Self Report Questionnaire (I. Petersen, Bhana, & Baillie, 2012; I Petersen, Hanass Hancock, Bhana, & Govender, 2014a; Scholte et al., 2011) and the SSQ. Five trials made use of diagnostic assessments, namely the Mini-International Neuropsychiatric Interview (MNI) (Andersen et al., 2016; Wagner et al., 2016), Structured Clinical Interview for DSM-IV-TR Axis I Disorders (SCID-1) (P Bolton et al., 2003; I Petersen et al., 2014a), and PHQ-9 (Chibanda et al., 2016; Wagner et al., 2016). The PHQ was the most used measure of symptom severity (Adams, Almond, Ringo, Shangali, & Sikkema, 2012a; Chibanda et al., 2016; Pence, Gaynes, Atashili, O'Donnell K., et al., 2014; Wagner et al., 2016) Acceptability and feasibility data was drawn from qualitative interviews (Brooke-Sumner, Lund, Selohilwe, & Petersen, 2017; Pence, Gaynes, Atashili, O'Donnell K., et al., 2014; I. Petersen, Bhana, & Baillie, 2012; I Petersen, Hanass Hancock, Bhana, & Govender, 2014a; Sorsdahl et al., 2015).

**Table 2-1 Measures used by included trials**

Phase	Measure	Number of trials using measure	Trials
<b>Screening</b>	PHQ-9	2	Adams 2012, Pence 2014,
	PHQ-2	1	Wagner 2016
	SSQ	2	Chibanda 2011, Chibanda 2016
	CES-D	1	Andersen 2016
	Functional assessment	1	Brooke-Sumner 2016
	mhGAP-IG	1	Musyimi 2017
	SRQ	3	Petersen 2012, Petersen 2014, Scholte 2011
	ASSIST	1	Sorsdahl
	EPDS	1	Tomlinson 2017
<b>Diagnostic</b>	MINI	2	Andersen 2016, Wagner 2016
	SCID	2	Bolton 2003, Petersen 2014
	PHQ-9	2	Chibanda 2016, Wagner 2016
<b>Symptom severity</b>	PHQ-9	4	Adams, Chibanda 2016, Pence 2014, Wagner 2016
	CES-D	2	Andersen 2016, Sorsdahl 2015
	HAM-D	1	Andersen 2016
	SSQ	2	Chibanda 2011, Chibanda 2016
	Hopkins Symptom Checklist	1	Bolton 2003
	GAD-7	1	Chibanda 2016
	BDI	1	Musyimi 2017
	PDS	1	Neuner 2008
	HSCL-25	1	Petersen 2014
	SRQ-20	1	Scholte 2011
	ASSIST	1	Sorsdahl
	EPDS	1	Tomlinson 2017
	Infant weight and height	1	Tomlinson 2017
<b>Adherence</b>	Adult AIDS Clinical Trials Group adherence measure;	1	Adams 2012
	Wisepill	1	Andersen 2016
<b>Acceptability</b>	Side effects	1	Adams 2012
	Qualitative questionnaires	4	Brooke-Sumner 2016, Pence 2014, ?Sorsdahl 2015, Petersen 2014
	Likert for lay workers	1	Chibanda 2011
<b>Feasibility</b>	Qualitative (Implementation challenges)	5	Brooke-Sumner 2016, Pence2014, Petersen 2012, Petersen 2014 ?Sorsdahl 2015
	Participant retention and dosage	1	Petersen 2012
<b>Fidelity</b>	Intervention fidelity by therapist	1	Andersen 2016
	MBC congruence	1	Pence 2014
<b>Functional outcomes</b>	SDS	1	Andersen 2016
	Sex-specific 9-item questionnaire	1	Bolton 2003
	WHODAS 2.0	1	Chibanda 2016
	Physical health checklist	1	Neuner 2008
	EQ-5D	1	Chibanda 2016
	MSPSS	1	Petersen 2014
	SPSI-R:SF	1	Sorsdahl 2015
<b>Safety</b>	Toxicity side effects	1	Pence 2014

**Table 2-2 Characteristics of included studies**

Study	Trial design	Setting	Sample size	Sample characteristics	Intervention	Control	Role of non-specialist workers	Measures	Review schedule
<i>Adams 2012</i>	Prospective cohort study, No comparison group	Outpatient HIV Care and Treatment Centre at a regional-level public hospital in the Northern Zone of Tanzania	Total: 20	<u>Sex:</u> Male: 6 (30%) Female: 14 (70%)  <u>Target diagnosis:</u> Depression	Measurement Based Care: Interval measurement of depressive symptoms, with adjustment of antidepressant dose based on symptom measure	None	<u>Intervention:</u> A nurse and clinical officer  <u>Study measures:</u> Study nurse	<u>Screening:</u> <ul style="list-style-type: none"> <li>Score <math>\geq 10</math> PHQ-9<sup>a</sup></li> </ul> <u>Outcomes:</u> <ul style="list-style-type: none"> <li>Symptom Severity - depressive symptoms PHQ-9;</li> <li>Adherence - Adult AIDS Clinical Trials Group adherence measure;</li> <li>Acceptability: Side Effects</li> </ul>	<ul style="list-style-type: none"> <li>Week 4,</li> <li>Week 8</li> <li>Week 12</li> </ul>
<i>Anderse n 2016</i>	Pilot intervention study, no comparison group	HIV care clinics in Khayelitsha, Cape, South Africa	Total: 14	<u>Age:</u> Range 28 - 59 years. Mean 38.4 SD 7.81  <u>Sex:</u> Male: 1 Female: 13  <u>Target diagnosis:</u> Depression	Ziphamandla: (CBT-AD) <sup>b</sup> 6-8 sessions, With standard antiretroviral treatment	None	<u>Intervention:</u> Nurses	<u>Screening:</u> Centre for Epidemiological Studies Depression Scale (CES-D).  <u>Diagnostic:</u> <ul style="list-style-type: none"> <li>Mini International Diagnostic Inter-view 6.0 (MINI)</li> </ul> <u>Outcomes:</u> <ul style="list-style-type: none"> <li>Intervention fidelity by therapist,</li> <li>Treatment attendance: Wisepill</li> <li>Centre for Epidemiological Studies Depression Scale (CES-D)</li> <li>Hamilton Depression Scale (HAM-D),</li> <li>Sheehan Disability Scale</li> </ul>	<ul style="list-style-type: none"> <li>3-month follow-up</li> </ul>

<sup>a</sup> Patient Health Questionnaire-9 item

<sup>b</sup> Cognitive behavioural therapy intervention for adherence and depression

Study	Trial design	Setting	Sample size	Sample characteristics	Intervention	Control	Role of non-specialist workers	Measures	Review schedule
<i>Bolton 2003</i>	Randomized controlled trial	Rakai and Masaka provinces in Southwest Uganda	Total: 341  Intervention: 163 in 15 villages Control: 178 in 15 villages	<u>Age:</u> Intervention: 47.4 (17.0); Control 45.2 (17.0)  <u>Sex:</u> Female No. (%): Intervention: 83 (51); Control 94 (53)  <u>Target diagnosis:</u> Depression	Group Interpersonal Psychotherapy:  90 minutes once a week for 16 weeks	No treatment	<u>Intervention:</u> Lay counsellors	<u>Screening:</u> <ul style="list-style-type: none"><li>Major depression or sub-syndromal depression Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)</li></ul> <u>Outcomes:</u> <ul style="list-style-type: none"><li>Depression: Hopkins Symptom Checklist</li><li>Functional impairment: Sex-specific 9-item questionnaire</li></ul>	<ul style="list-style-type: none"><li>Week 2 post intervention</li><li>6 month (Bass paper)</li></ul>
<i>Brooke-Sumner 2016</i>	Formative, non-controlled	PH clinic in Kanana, North West Province, South Africa	6	<u>Age:</u> All above age 45  <u>Sex:</u> Females: 2  <u>Target diagnosis:</u> Schizophrenia	PRIME South Africa Development of a community based psychosocial rehabilitation programme.	None	<u>Referrals:</u> Community health workers  <u>Screening:</u> Clinical psychologist  <u>Intervention:</u> Auxiliary Social Workers	<u>Screening:</u> <ul style="list-style-type: none"><li>Functional assessment incorporating a mini mental-status exam and assessment of cognition</li></ul> <u>Outcomes:</u> <ul style="list-style-type: none"><li>Acceptability and feasibility: Qualitative interviews</li></ul>	<ul style="list-style-type: none"><li>Baseline</li><li>Week 6,</li><li>Week 12</li></ul>
<i>Chibanda 2011</i>	Pilot intervention trial, non-controlled	Mbare, Harare, Zimbabwe	320	<u>Age:</u> 21-41	Friendship Bench intervention	None	<u>Intervention:</u> Lay health worker	<u>Screening:</u> <ul style="list-style-type: none"><li>Shona Symptom Questionnaire for common mental disorders 7 item (SSQ): 7</li></ul>	<ul style="list-style-type: none"><li>Baseline,</li><li>6 weeks.</li></ul>

Study	Trial design	Setting	Sample size	Sample characteristics	Intervention	Control	Role of non-specialist workers	Measures	Review schedule
Chibanda 2016	Cluster randomized controlled trial	Health care Clinics in Harare, Zimbabwe	Total: 576 Intervention: 286 Control: 287	<u>Sex:</u> Male: 97 (30%) Female: 223 (70%)  <u>Target diagnosis:</u> Common mental disorders	Friendship Bench intervention: Six sessions of a PST package which is delivered on a bench in a discrete area outside of the local clinic  Six sessions within 4-6 weeks, 30–45 min with the first session lasting up to an hour.	Enhanced Usual Care:  Standard care with information, education, and support on common mental disorders.	<u>Study measures:</u> Research nurse  <u>Intervention:</u> Lay health workers	<u>Outcomes:</u> <ul style="list-style-type: none"> <li>Main outcome measure was the Shona Symptom Questionnaire (SSQ),</li> <li>Evaluation of PST intervention: Likert scale for the lay workers</li> </ul>	
				<u>Age:</u> Mean (SD) Intervention: 33.4 (10.6) Control: 36.7 (12.5)  <u>Sex:</u> Male: Intervention: 32 (11.2%) Control: 46 (16.0%) Female: Intervention: 254 (88.8%) Control: 241 (84.0%)  <u>Target diagnosis:</u> Depression				<u>Screening:</u> <ul style="list-style-type: none"> <li>Presence of a Common Mental Disorder: Shona Symptom Questionnaire (SSQ-14)</li> <li>Clinical diagnosis of depression: PHQ-9.</li> </ul> <u>Outcomes:</u> <ul style="list-style-type: none"> <li>Primary outcome was Shona Symptom Questionnaire 14 item (SQ-14)</li> <li>Secondary outcome was <ul style="list-style-type: none"> <li>Prevalence of major depressive disorder symptoms based on the 9-item Patient Health Questionnaire (PHQ-9),</li> </ul> </li> <li>Tertiary outcomes : <ul style="list-style-type: none"> <li>Generalized Anxiety Disorder 7-item Scale (GAD-7),</li> <li>World Health Organization Disability Assessment Schedule version 2.0 (WHODAS 2.0); and</li> <li>Quality of life EuroQOL 5D (EQ-5D) total score</li> </ul> </li> </ul>	

Study	Trial design	Setting	Sample size	Sample characteristics	Intervention	Control	Role of non-specialist workers	Measures	Review schedule
<i>Musyimi 2017</i>	longitudinal non-randomized interventional study	Makueni County, located in the arid and semi-arid zones of the Eastern region of Kenya	377	<u>Age:</u> Mean 46 SD 17  <u>Sex:</u> Male: 112 (29.7%) Female: Female 265 (70.3%)  <u>Target diagnosis:</u> Depression	mhGAP-IG <sup>c</sup> psychosocial intervention  Traditional Health Practitioners delivered psychosocial interventions to patients screening positive for mild to severe depression	None	<u>Intervention:</u> Traditional health practitioners  <u>Study measures:</u> Community health workers	<u>Screening:</u> Screen-positive for depression: mhGAP-IG  <u>Outcomes:</u> The Beck Depression Inventory (BDI),	<ul style="list-style-type: none"> <li>• Baseline</li> <li>• 6 weeks</li> <li>• 12 weeks</li> </ul>
<i>Neuner 2008</i>	Randomized controlled trial	The Nakivale refugee settlement in Uganda	277	<u>Age:</u> M (SD) NET: 34.4 (12.2); TC: 35.2 (12.8); MG: 35.6 (14.0)  <u>Sex:</u> n (%) - Males NET: 55 (49.5); TC: 28 (50.9) MG: 52 (46.8);  <u>Target diagnosis:</u>	<u>Intervention 1:</u> Strictly manualized narrative exposure therapy (NET)  <u>Intervention 2:</u> Trauma counseling (TC)	No-treatment monitoring group (MG)	<u>Intervention:</u> Lay health workers selected in the camp	<u>Outcomes:</u> <ul style="list-style-type: none"> <li>• PTSD diagnosis and severity: Posttraumatic Stress Diagnostic Scale (PDS)</li> <li>• Physical health: Assessed with a checklist of</li> </ul>	<ul style="list-style-type: none"> <li>• Baseline,</li> <li>• 3 months</li> <li>• 6 months</li> <li>• 9 months</li> </ul>

<sup>c</sup> Mental Health Action Gap Programme-Intervention Guide

Study	Trial design	Setting	Sample size	Sample characteristics	Intervention	Control	Role of non-specialist workers	Measures	Review schedule
<i>Pence 2014</i>	PTSD								
	Prospective pilot study	Bamenda Regional Hospital/ Bamenda Day Hospital AIDS Treatment Centre in Cameroon	55	<u>Age:</u> 24 - 53 (median 40).  <u>Sex:</u> Male 11 (20 %) Female 44 (80 %)  <u>Target diagnosis:</u> Depression	Measurement-based care (MBC) with the use of Amitriptyline <sup>d</sup> and standard ART  A Depression Care Manager guides a non-mental health practitioner in management with antidepressant treatment	None	<u>Screening:</u> Treating HIV <sup>e</sup> physician  <u>Study measures:</u> Psychiatric nurse	<u>Screening:</u> <ul style="list-style-type: none"> <li>PHQ-9</li> <li>Current major depressive episode</li> </ul> <u>Outcomes:</u> <ul style="list-style-type: none"> <li>Feasibility:</li> <li>Fidelity: Congruency between the MBC recommendations and the HIV provider's treatment decision</li> <li>Acceptability</li> <li>Preliminary efficacy: Remission of depression (PHQ-9 total score\5) at each time point</li> <li>Safety: Measured by the presence of signs and symptoms of anticholinergic toxicity</li> </ul>	<u>Clinical decision points:</u> <ul style="list-style-type: none"> <li>Baseline</li> <li>Weeks 4</li> <li>Week 8</li> <li>Week 12</li> </ul> <u>Side effect monitoring:</u> <ul style="list-style-type: none"> <li>Weeks 2</li> <li>Week 6</li> <li>Week 10</li> </ul>
<i>Petersen 2012</i>	Controlled pilot study, non-randomized	Clinic in the Hlabisa sub-district in northern KwaZulu-Natal, South Africa	Total 42	<u>Age:</u> Above 18 years  <u>Sex:</u> Female (42) 100%  <u>Target diagnosis:</u> Depression	Adapted Group-Based Interpersonal Therapy (IPT):  16 sessions over 12 weeks	Enhanced standard care: Care by PHC nurses with intervention training	<u>Screening:</u> Mental health counsellor  <u>Intervention:</u> Community health workers  <u>Study measures:</u> ?	<u>Screening:</u> Self-reporting Questionnaire (SRQ); Beck Depression Inventory (BDI)  <u>Outcomes:</u> <ul style="list-style-type: none"> <li>Feasibility: In-depth interviews for process evaluation; participant retention and dosage</li> <li>Beck Depression Inventory (BDI) - depressive symptoms; Feasibility - Hopkins Symptom Checklist (HSCL-25), Beck Depression Inventory (BDI)</li> </ul>	<ul style="list-style-type: none"> <li>Baseline</li> <li>Week 12</li> <li>Week 24</li> </ul>

<sup>d</sup> Amitriptyline is a tricyclic antidepressant

<sup>e</sup> Human Immunodeficiency Virus

Study	Trial design	Setting	Sample size	Sample characteristics	Intervention	Control	Role of non-specialist workers	Measures	Review schedule
<i>Petersen 2014</i>	Controlled, Randomized	Public clinic in a peri-urban area outside of Durban, KwaZulu-Natal, South Africa	Total: 34 Intervention:17 Control:17	<u>Age:</u> 21–30: 12(35%); 31–40: 10(29%); 41–50: 7(21%); 51–59: 5(15%)	Group-based interpersonal therapy IPT:  With standard antiretroviral treatment	Normal standard of care which included the counselling services provided by the HIV counsellors	<u>Screening:</u>  <u>Diagnostic:</u> Clinical psychologist  <u>Intervention:</u> Lay counsellors  <u>Study measures:</u> Counselling psychologist	<u>Screening:</u> <ul style="list-style-type: none"> <li>Self-Reporting Questionnaire (SRQ-20)</li> </ul>	<ul style="list-style-type: none"> <li>Baseline</li> <li>Week 12</li> </ul>
				<u>Sex:</u> Male: 9(26%). Female: 25(74%)				<u>Screening/Diagnostic:</u> <ul style="list-style-type: none"> <li>Structural Clinical Interview for a DSMIV Diagnosis (SCID-1) – Depression Module</li> </ul> <u>Outcomes:</u> <ul style="list-style-type: none"> <li>Depression severity: Patient Health Questionnaire (PHQ9) and</li> <li>Psychological functioning: Hopkins Symptoms Checklist (HSCL-25).</li> <li>Social support: The Multidimensional Scale of Perceived Social Support (MSPSS).</li> <li>Process evaluation: User and lay worker interviews</li> </ul>	
<i>Scholte 2011</i>	Quasi-experimental study, non-randomized	Rwanda	Total: 200 Intervention: 100 Control: 100	<u>Age:</u> Mean Age - Experimental group: 34.9; Control group: 38.5  <u>Sex:</u> Male: Experimental group: 45 (45%); Control group: 47 (47%); Female: Experimental group: 55 (55%); Control group: 53 (53%)	Sociotherapy:  Psychosocial intervention aimed at social bonding	No intervention.	<u>Intervention:</u> Local lay people as group leaders	<u>Screening:</u> Self-Reporting Questionnaire (SRQ-20)  <u>Outcomes:</u> Total SRQ-20	<ul style="list-style-type: none"> <li>Baseline</li> <li>Directly post intervention</li> <li>Month 8</li> </ul>



Study	Trial design	Setting	Sample size	Sample characteristics	Intervention	Control	Role of non-specialist workers	Measures	Review schedule
<i>Sorsdahl 2015</i>	Randomized controlled trial	One of three 24-hr emergency departments in Cape Town	Total: 335 MI: 113 MI-PST: 112 CG: 110	<u>Target diagnosis:</u>  Psychological sequelae of war and genocide	Intervention 1:  Motivational Interviewing  Intervention2: Blended Motivational interviewing and Problem Solving Therapy	Psychoeducational control group	<u>Intervention:</u>  Peer-counsellor	<u>Screening:</u>  • Substance Use involvement: Alcohol, Smoking, and Substance Involvement Screening Test (ASSIST)	<u>Outcomes:</u>  • Acceptability • Feasibility • Substance Use involvement: Alcohol, Smoking, and Substance Involvement Screening Test (ASSIST) • Problem solving. The Social Problem-Solving Inventory-Revised, Short Form (SPSI-R:SF) • The Centre for Epidemiological Studies Depression scale (CES-D)
				<u>Age:</u> mean, range  28 (18-75)  <u>Sex:</u> Male: 218 (65.5%). Female: 115(34.5%)  <u>Target diagnosis:</u>  Substance use disorders  Depression,					
<i>Tomlinson 2017</i>	Controlled, Randomized	Cape Town	Total: 1238	<u>Age:</u> Mean age (SD) - 26.4 (5.5)  <u>Sex:</u> Female  <u>Target Diagnosis:</u> Depression	Philani Intervention Program (PIP), with antiretroviral treatment, co-trimoxazole, nutritional supplements	Standard care	Intervention:  Mentor mother CHW	<u>Screening:</u>  Edinburgh Postnatal Depression Scale (EPDS).  <u>Outcomes:</u>  Maternal depression - the Edinburgh Postnatal Depression Scale (EPDS)  Infant measures - Weight and length  Standardized z-scores (height-for-age, weight-for-age, height-for-weight-for age)	• Baby's birth, Post-birth Assessment, • 6-Month Assessment, • 18-Month Assessment

Study	Trial design	Setting	Sample size	Sample characteristics	Intervention	Control	Role of non-specialist workers	Measures	Review schedule
<i>Wagner 2016</i>	Cluster Randomized Trial	HIV outpatient Clinics - 10 health care facilities in Uganda	Total: 1252	<u>Age:</u> Mean (SD) Age: 40.0 (11.2).	Structured Protocol Model of Depression Care, with antiretroviral treatment and HIV medication	Clinical acumen		<u>Screening:</u> Patient Health Questionnaire (PHQ); PHQ-2;	
			Intervention: 640	<u>Sex:</u> Female (%) 76.8%.				<u>Diagnostic:</u> PHQ-9; MINI.	
			Control: 612	<u>Target diagnosis:</u> Depression				<u>Outcomes:</u> PHQ-9	

**Table 2-3 Description of excluded records**

Study	Location	Title	Investigation procedures	Reason for Exclusion
Asmal 2014	Stellenbosch	Towards a treatment model for family therapy for schizophrenia in an urban African setting: Results from a qualitative study.	Psycho-educational and behaviour modification.	Intervention delivered by experienced trained psychiatric nurse
Chibanda 2015	Zimbabwe	The Friendship Bench programme: a cluster randomized controlled trial of a brief psychological intervention for common mental disorders delivered by lay health workers in Zimbabwe	The Friendship Bench: Six session problem-solving therapy	Protocol for Chibanda 2016
Davies 2016	Khayelitsha	“The sun has set even though it is morning”: Experiences and explanations of perinatal depression in an urban township, Cape Town	Semi-structured interviews	Formative Qualitative
Hanlon 2016	Ethiopia	Task sharing for the care of severe mental disorders in a low-income country (TaSCS): study protocol for a randomized controlled, non-inferiority trial	Primary-health care-integrated local care for MHSU with SMI	Ongoing study, delivered by mental health nurses
Igberas 2012	Benin	Burden of care among relatives of patients with schizophrenia in Midwestern Nigeria	Cross sectional using the Burden Questionnaire for caregivers and the PANSS for MHSU	No intervention
James 2014	Nigeria	Clergy as collaborators in the delivery of mental health care: An exploratory survey from Benin City, Nigeria	Exploratory survey	Cross sectional, no intervention
Labys 2016	KwaZulu-Natal	Psychosis and help-seeking behaviour in rural KwaZulu-Natal: unearthing local insights	Cross sectional	No intervention
Lund 2014	Khayelitsha	Task sharing of a psychological intervention for maternal depression in Khayelitsha, South Africa: study protocol for a randomized controlled trial	Psychosocial intervention	Completed, unpublished

Study	Location	Title	Investigation procedures	Reason for Exclusion
Mbwayo 2013	Kenya	Traditional healers and provision of mental health services in cosmopolitan informal settlements in Nairobi, Kenya	Focus groups and in-depth interviews	Cross sectional, no intervention
Mendenhall 2014	Multisite	Acceptability and feasibility of using non-specialist health workers to deliver mental health care: Stakeholder perceptions from the PRIME <sup>f</sup> district sites in Ethiopia, India, Nepal, South Africa, and Uganda	Focus group and in-depth interviews to establish the acceptability and feasibility of task-sharing	Cross sectional, no intervention
Temmingh 2013	South Africa	The Evaluation of a Telephonic Wellness Coaching Intervention for Weight Reduction and Wellness Improvement in a Community-Based Cohort of Persons with Serious Mental Illness	Telephonic lifestyle coaching intervention	Not task shifting
van Ginneken 2013	Multisite	Non-specialist health worker interventions for the care of mental, neurological and substance-abuse disorders in low- and middle- income countries (Review)	Review	Not an intervention
Wagner 2014	Uganda	INtegration of DEPression Treatment into HIV Care in Uganda (INDEPTH-Uganda): study protocol for a randomized controlled trial	Structured Protocol Model of Depression Care, with antiretroviral treatment and HIV medication vs Clinical Acumen	Protocol for Wagner 2016

<sup>f</sup> PRogramme for Improving Mental health carE

### **2.3.3 Risk of bias of included studies**

The risk of bias assessments of included studies is presented in Tables 2-4 for the RCTs and Table 2-5 for the non-randomized trials. The RCTs were generally of good quality with a low overall risk of bias. The non-randomized trials while largely of good quality were generally of moderate risk of bias.

**Table 2-4 Assessment risk of bias for randomized controlled trials**

<i>Study</i>	<b>Sequence generation</b>	<b>Allocation concealment</b>	<b>Performance bias</b>	<b>Detection bias</b>	<b>Incomplete outcome data</b>	<b>Selective outcome reporting</b>	<b>Other</b>	<b>Overall</b>
<i>Bolton 2013</i>	Low:  Random assignment was performed by enumerating the villages and using a random-number table to determine study allocation Random sequence generation method should produce comparable groups	Unclear:  Not described in sufficient detail	Unclear:  Not described in sufficient detail to infer blinding.	Unclear:  Effectiveness of blinding not described. Interviewers may have recalled the participants villages of origin.	Low:  Attrition rates similar, no significant difference in confounders, accounted for missing participants, used ITT	Unclear:  Insufficient information to permit judgment.	Low:  No other bias detected.	Low to unclear
<i>Chibanda 2016</i>	Unclear:  Not described in sufficient detail. It is indicated that participants were randomized, but randomization sequence generation not described.	Low:  Public randomization exercise was carried out by city health staff not involved in the study. The entire study team was blinded to this exercise.	Low:  Blinding was likely effective. The research assistants responsible for outcome assessment were masked to the allocation.	Low:  The SSQ-14 was administered by a blinded research assistant, with the entire study team blinded to the exercise.	Low:  Handling of incomplete outcome data was complete and unlikely to have produced bias	Low:  Selective outcome reporting bias not detected.	Low:  No other bias detected.	Low
<i>Neuner 2008</i>	Unclear:	Unclear:	Low:	Low:		Unclear:	Low:	Low to unclear

<i>Study</i>	<b>Sequence generation</b>	<b>Allocation concealment</b>	<b>Performance bias</b>	<b>Detection bias</b>	<b>Incomplete outcome data</b>	<b>Selective outcome reporting</b>	<b>Other</b>	<b>Overall</b>
	Not described in sufficient detail. Stratification strategy not described.	Not described in sufficient detail	Research assistants who conducted measures were blinded to the treatment condition. Blinding was likely effective.	Research assistance conducting study measures were blinded to the treatment allocation. Blinding was likely effective.		Insufficient information to permit judgment†	No other bias detected. One potential source would have been nationality; however, this was well accounted for.	
<i>Petersen 2014</i>	Low:  Computer-generated allocation sequence.	Low:  Individual conducting allocations was blinded to the screening scores.	Unclear:  Not described in sufficient detail to infer blinding.	Unclear:  Not described in sufficient detail.	Unclear:  Insufficient information available.	Unclear:  Insufficient information to permit judgment.	Low:  No other bias detected.	Unclear
<i>Sorsdahl 2015</i>	Low:  "generated by random number tables by a research worker not involved in the delivery of the intervention"	Low:  "Treatment allocation was by numbered sealed, opaque envelopes by a research worker not involved in the delivery of the intervention"	Low:  Interviewers performing follow-up outcome assessments were blinded to treatment condition.	Low:  Interviewers performing follow-up assessments were blinded to treatment allocation.	Low:  Similar dropouts across the three groups. Demographics reported on including reasons for attrition. Intention to treat analysis.	Unclear:  Insufficient information to permit judgment.	Low:  No other bias detected.	Low to unclear
<i>Tomlinson 2017</i>	Unclear:	Unclear:	Unclear:	Low:	Low:	Unclear:	Low:	Low to unclear

<i>Study</i>	<b>Sequence generation</b>	<b>Allocation concealment</b>	<b>Performance bias</b>	<b>Detection bias</b>	<b><i>Incomplete outcome data</i></b>	<b><i>Selective outcome reporting</i></b>	<b><i>Other</i></b>	<b><i>Overall</i></b>
<i>Wagner 2016</i>	Not described in sufficient detail. Indicated participants were randomized, however sequence generation not described.	Not described in sufficient detail.	Not described in sufficient detail.	Research assistants performing follow-up outcome assessments were blinded to treatment condition.	Similar dropouts across groups (16%). There were no significant differences found in baseline demographic characteristics.	Insufficient information to permit judgment†	No other bias detected.	
	Unclear:  Randomization is described, however sequence generation not described.	High:  No masking to model assignment.	High:  No masking performed.	High:  No masking performed.	Low:  Similar dropouts across groups (16%). There were no significant differences found in baseline demographic characteristics.	Low:  Fully reported. Selective outcome reporting bias not detected	Low:  Funding role fully described.	High



**Table 2-5 Assessment of quality for non-randomized trials**

<i>Study</i>	<i>Bias due to confounding</i>	<i>Bias in selection of participants into the study</i>	<i>Bias in classification of interventions</i>	<i>Bias due to deviations from intended interventions</i>	<i>Bias due to missing data</i>	<i>Bias in measurement of outcomes</i>	<i>Bias in selection of the reported result</i>	<i>Overall</i>
<i>Adams 2012</i>	Low:  Appropriate methods to control for confounding domains. No additional confounding factors introduced and controlled for post intervention.	Moderate:  Lack of systematic screening to identify participants could have created a bias for self-selection of highly motivated participants and thus an over-estimation of acceptability and feasibility. convenience sampling was used.	Low:  Interventions groups clearly defined. Information used to define intervention groups recorded at intervention start, Classification of intervention status could not have been affected by knowledge of outcome or risk of outcome.	Low:  Few deviations in the intended interventions. Only participants withdrew throughout the study. Only one group.	Low:  Outcome data available for nearly all participants. Participants were not excluded due to missing data on intervention status. Participants were excluded due to missing data on variables needed for analysis. Only one intervention, no comparison.	Moderate:  No blinding. Outcome assessors were aware of interventions received. Methods of outcome assessment were comparable across the two groups.	Unclear –  Published protocol not found	Moderate
<i>Andersen 2016</i>	Unclear:  Not discussed in the analysis section. However confounding variables accounted for in the demographics tables. Statistical differences were not reported. The almost exclusively female sample may limit generalizability of findings to men.	Moderate:  Mostly female sample may limit generalizability of findings. Differing recruitment procedure used depending on clinic setting.	Low:  Interventions groups clearly defined. Information used to define intervention groups recorded at intervention start, Classification of intervention status could not have been affected by knowledge of outcome or risk of outcome.	Low:  No comparison group. Retention was high, intervention implemented successfully for most participants (12/14). Not all participants adhered to assigned intervention regimen, 2 lost to follow up. Appropriate analysis used to estimate effect of starting	Low:  Outcome data available for nearly all participants "In all, 12 of the 14 patients completed the Ziphamandla treatment." Participants were not excluded due to missing data on intervention status. Participants not excluded due to missing data on variables need for analysis "Three-	Moderate:  No blinding. Outcome assessors were aware of interventions received. Only one group.	Unclear –  Published protocol not found	

<i>Study</i>	<i>Bias due to confounding</i>	<i>Bias in selection of participants into the study</i>	<i>Bias in classification of interventions</i>	<i>Bias due to deviations from intended interventions</i>	<i>Bias due to missing data</i>	<i>Bias in measurement of outcomes</i>	<i>Bias in selection of the reported result</i>	<i>Overall</i>
				and adhering to intervention.	month follow-up data were obtained from 11 of the 12 participants who completed treatment and from one of the two participants who discontinued treatment". Only one intervention arm. There is evidence that results are robust "with a very large effect size (Cohen's $d = 3.8$ )."			
<i>Brooke-Sumner 2016</i>	Moderate:  This is a qualitative study. Although the demographics of the sample were discussed narratively. No information in the analysis section was provided on confounding variables nor in the discussion section.	Low:  Selection of participants well detailed.	Low:  Interventions groups clearly defined. Information used to define intervention groups recorded at intervention start, Classification of intervention status could not have been affected by knowledge of outcome or risk of outcome.	Low:  No co-intervention. Retention was good, 6 out of 7 participants attended regularly. Study participants adhered to intervention regimen. Data was qualitative.	Moderate:  Overall retention good. Qualitative study, single missing no that impactful. Only 14 participants.	Moderate:  No blinding. Outcome assessors were aware of interventions received. Only one group.	Unclear:  Published protocol not found	Moderate
<i>Chibanda 2011</i>	Unclear:	Low:	Low:	Low:	Low:	Moderate:	Low:	Low to moderate

<i>Study</i>	<i>Bias due to confounding</i>	<i>Bias in selection of participants into the study</i>	<i>Bias in classification of interventions</i>	<i>Bias due to deviations from intended interventions</i>	<i>Bias due to missing data</i>	<i>Bias in measurement of outcomes</i>	<i>Bias in selection of the reported result</i>	<i>Overall</i>
<i>Musyimi 2017</i>	Demographic table provided although no information on differences between groups. Analysis method controlling for confounders not clearly described.	Analysis accounted for participants, declines and losses to follow up.	Interventions groups clearly defined. Information used to define intervention groups recorded at intervention start, Classification of intervention status could not have been affected by knowledge of outcome or risk of outcome.	No co-intervention. Ninety percent of participants completed intervention activities. Retained study participants adhered to intervention regimen.	Outcome data available for nearly all participants "88% response rate (n = 320)." Participants were not excluded due to missing data on intervention status. Participants not excluded due to missing data on variables need for analysis "Descriptive statistics (means and standard deviations and proportions) were estimated for those who participated, who declines, who were lost to follow, and who were excluded due to psychiatric risk."	No blinding. Self-administered measures. Only one group.	All outcomes accounted for. No deviation from protocol.	
	Low:  Demographic data accounted for in analysis as covariates.	Low:  Analysis accounted for participants, declines and losses to follow up.	Low:  Interventions groups clearly defined. Information used to define intervention groups recorded at intervention start, Classification of intervention status could not have been	Low:  No co-intervention. Nineteen percent of participants were lost to follow up. All participants with at least one assessment after baseline included in analysis.	Low:  Outcome data available for nearly all participants. Participants were not excluded due to missing data on intervention status. No Participants not excluded due to missing data on	Serious:  Blinding not specified. Partly self-administered measures. Interviewer blinding not detailed for non-self-administered. Only one group.	Unclear –  Published protocol not found	Moderate

<i>Study</i>	<i>Bias due to confounding</i>	<i>Bias in selection of participants into the study</i>	<i>Bias in classification of interventions</i>	<i>Bias due to deviations from intended interventions</i>	<i>Bias due to missing data</i>	<i>Bias in measurement of outcomes</i>	<i>Bias in selection of the reported result</i>	<i>Overall</i>
			affected by knowledge of outcome or risk of outcome.		variables need for analysis "Following the paired sample t-test for pair-wise comparisons across the 3 time points, there was no significant outcome difference between patients who dropped out and those who were assessed at all time points."			
<i>Pence 2014</i>	Moderate:  Gender is significant confounder, for which not well described. Subjects with death and comorbidity adverse events excluded from analysis.	Low:  Two participants lost due to events unrelated to intervention (death and alcohol consumption).	Low:  Interventions groups clearly defined. Information used to define intervention groups recorded at intervention start, Classification of intervention status could not have been affected by knowledge of outcome or risk of outcome.	Moderate:  No comparison group. Retention was high, intervention implemented successfully for most participants. Intervention fidelity high. Not all participants adhered to assigned intervention regimen, total of 74 out of 80 study visits attended. Analysis details not clear on handling of lost participants.	Low:  Outcome data available for nearly all participants "The 4-, 8-, and 12-week CDPs were completed by 100 % (55/55), 93 % (50/54), and 100 % (53/53) of remaining participants, respectively". Participants were not excluded due to missing data on intervention status. Participants not excluded due to missing data on	Moderate:  Self-administered measures. Blinding not detailed. Only one group.	Unclear:  Published protocol not found	Moderate

<i>Study</i>	<i>Bias due to confounding</i>	<i>Bias in selection of participants into the study</i>	<i>Bias in classification of interventions</i>	<i>Bias due to deviations from intended interventions</i>	<i>Bias due to missing data</i>	<i>Bias in measurement of outcomes</i>	<i>Bias in selection of the reported result</i>	<i>Overall</i>
					variables need for analysis.			
<i>Petersen 2012</i>	Unclear:  Loss to follow up not explained in the analysis nor in the results re demographics and statistical significance.	Moderate:  Non-random selection may have resulted in selection bias.	Moderate:  Interventions groups clearly defined. Information used to define intervention groups recorded at intervention start. Classification of intervention status could have been affected by knowledge of outcome or risk of outcome. "Assignment was non-random and based on practicalities of whether eligible participants were available to participate in a 12-week group intervention as well as the availability of space within a group at the time of screening"	Low:  No co-intervention. Seventy seven percent of participants completed the programme. Over 50% participants attended all 11-12 sessions. Only intervention completers analysed.	Moderate:  Outcome data available for nearly all participants "Group retention was good, with 23 (77%) completing the programme over the 12-week period. Dosage was equally good, with all remaining 23 participants attending 8–12 group sessions, with over 50% attending all 11–12 sessions. Participants were not excluded due to missing data on intervention status. Participants were excluded due to missing data on variables need for analysis "Analysis of the data for participants who completed all three assessments indicates that the IPT intervention led to a significant	Moderate:  No blinding. Outcome assessors aware of interventions received. Methods of outcome assessment comparable across the two groups.	Unclear:  Published protocol not found	Moderate

<i>Study</i>	<i>Bias due to confounding</i>	<i>Bias in selection of participants into the study</i>	<i>Bias in classification of interventions</i>	<i>Bias due to deviations from intended interventions</i>	<i>Bias due to missing data</i>	<i>Bias in measurement of outcomes</i>	<i>Bias in selection of the reported result</i>	<i>Overall</i>
					reduction in depressive symptoms as measured by the BDI in the intervention participants (n = 20) compared to the controls (n = 22) over a 12 and 24-week period" 5.4 Yes Proportion of missing data is similar across interventions (the other being controls).			
<i>Scholte 2011</i>	Low:  Confounders controlled for. Intention to treat analysis.	Low:  Between-group baseline difference in socioeconomic status not considered seriously impactful.	Low:  Interventions groups clearly defined. Information used to define intervention groups recorded at intervention start, Classification of intervention status could not have been affected by knowledge of outcome or risk of outcome.	Low:  No co-intervention. Most (73%) of participants completed study activities. Some participants in both groups lost to follow up. Intention to treat analysis.	Low:  Outcome data available for nearly all participants. Participants were not excluded due to missing data on intervention status. Participants not excluded due to missing data on variables need for analysis. Intention to Treat Analysis.	Moderate:  Blinding described but interviewers may still have recognized interviewees from randomized regions. Outcome assessors may have been aware of interventions received. Methods of assessment were comparable across the two groups.	Unclear:  Published protocol not found	Low

#### **2.3.4 Results of interventions**

Adams had good retention and good intervention fidelity by the DCM (Adams et al., 2012a). There was however poor follow-through of antidepressant dosing recommendations, which may have been a direct result of poor antidepressant availability. In spite of this, depression scores decreased from baseline over the 12-week period. The algorithm-based nursing support approach for prescription decisions was feasible. Recommendations included the importance of addressing medication supply challenges.

Andersen et al found robust improvements in mood through 3-month follow up (Andersen et al., 2016). There was good maintenance of antiretroviral therapy and the good participant retention suggested the intervention was acceptable. Provider fidelity was assessed as being modest despite supervision suggesting that component requires some additional attention to ensure feasibility.

The participants in Brooke-Sumner et al reported gaining benefit from the programme (Brooke-Sumner et al., 2017). This included better self-esteem, improved social support and mental health literacy, self-care, and felt they had begun to contribute more within their households. The non-provision of income generating opportunities was seen as a barrier to acceptability. Feasibility challenges included difficulties in tracking down service users and families, the lack of space to conduct study activities, as well as problems with the supply of antipsychotic medication.

In 2011 Chibanda et al found that 166 (52%) participants had presented with HIV-related problems (Chibanda et al., 2011b). The mean SSQ score fell from 11.3 (sd 1.4) before treatment to 6.5 (sd 2.4) after 3-6 Friendship Bench sessions. The drop in scores increased with the number of sessions attended, inferring a possible dose effect. Nine out of the 10 lay workers felt competent in delivering the PST intervention.

In the second Friendship Bench intervention, participants who had received the intervention were found to have fewer symptoms than participants in the control group on the SSQ-14 (3.81; 95%CI, 3.28 to 4.34 vs 8.90; 95%CI, 8.33 to 9.47; adjusted mean difference, -4.86; 95%CI, -5.63 to -4.10;  $P < .001$ ; adjusted risk ratio [ARR], 0.21; 95%CI, 0.15 to 0.29;  $P < .001$ ) (Chibanda et al., 2016). Additionally, participants in the Intervention group were noted to have a lower risk of symptoms of depression (13.7%vs 49.9%; ARR, 0.28; 95%CI, 0.22 to 0.34;  $P < .001$ ). The LHW-administered problem-solving focused and psychoeducation-based Friendship Bench intervention, resulted in symptomatic improvement at 6 months.

Musyimi et al found that BDI mean score was 26.52 before intervention and had significantly reduced at 6 (13%) and 12 (35%) weeks after the intervention (Musyimi, Mutiso, Ndeti, Henderson, & Bunders, 2017a). 58 and 78% of patients showed reduction in symptoms of depression at 6 and 12 weeks respectively, suggesting that traditional health practitioners may be a useful resource in treatment packages for depression and potentially other mental disorders.

Fewer participants (4%) dropped out of NET treatment than TC (21%) in the Neuner trial (Neuner et al., 2008). Both NET and TC were superior to MG in achieving reduction of PTSD symptoms and improvements in physical health, but neither was superior to the other. At follow-up, a PTSD diagnosis could not be established anymore in 70% of NET and 65% TC participants. Only 37% in the MG group no longer met PTSD criteria. Findings suggested that short-term psychotherapy delivered by minimally trained lay counsellors can be used to effectively treat war-related PTSD in a such a refugee settlement.

Pence et al enrolled 55 participants who all started amitriptyline at a dose of 25–50 mg daily at baseline (Pence, Gaynes, Atashili, O'Donnell K., et al., 2014). At 12 weeks, most had remained at a dose of 50 mg daily (range 25–125 mg). PHQ-9 scores indicating depression severity (median, IQR) declined from 13 (12–16) at baseline to 2 (0–3) at 12 weeks; 87 % achieved depression remission (PHQ-9  $\leq 5$ ) by 12 weeks. Intervention fidelity was high with HIV providers following MBC guidelines



96 % of the time. Most divergences occurred as a result of failure to increase amitriptyline dose when this was indicated. No serious side effects were noted, and only a few troublesome ones were. Suicidality, with a prevalence of 62 % at baseline and 8 % at 12 weeks, was assessed as being either passive or low-risk. All participants expressed satisfaction with the intervention, with 89% indicating they would be willing to pay for antidepressant medication if the MBC were implemented in standard care. The adapted MBC intervention was therefore highly feasible, safe and acceptable, demonstrating preliminary efficacy.

In 2012 the Petersen study reported good retention (I. Petersen et al., 2012). Participants who had received the group-based interpersonal therapy had significantly reduced depressive symptoms at the end of the 12-week intervention, an improvement which was maintained at 24 weeks from baseline compared to those in the control group. Qualitative investigations suggested that some of the factors which assisted in the reduction of depressive symptoms included better social support, personal coping skills and an improved capacity to act independently.

The 2014 Petersen trial 2014 found significantly greater improvement in depression scores on the PHQ9 in the group that received the intervention, compared to the control group (I Petersen et al., 2014a). While both groups had a significant decrease in HSCL-25 mean scores, the change was more pronounced for the intervention group. MPSS scores showed no significant improvement. The finding of this study, while preliminary, suggest that group-based IPT for depression in HIV-positive patients has the potential to be delivered effectively by lay HIV counsellors with appropriate training and support.

Eighty-one percent intervention-group and 73% of the control group in Scholte et al. received follow up measurements (Scholte et al., 2011). There was a decrease by 2.3 points in mean SRQ-20 scores in the experimental group compared with a 0.8 points decrease in the control group ( $p = 0.033$ ). Female intervention participants who had scored above the cut-off at baseline improved by 4.8 points to below cut-off ( $p, 0.001$ ). Males with baseline scores above cut-off showed a similar

improvement trend but this failed to reach statistical significance. There were no adverse events reported. This large scale psychosocial intervention targeting social bonding resulted in a lasting improvement in mental health amongst survivors of mass violence in Rwanda.

Sorsdahl et al randomized 335 participants to 1) Motivational interviewing (MI) (n= 113), 2) Motivational interviewing with problem-solving therapy( MI-PST) (n= 112); and 3) the control group (CG) (n= 110) (Sorsdahl et al., 2015). Three-month ASSIST scores were lower in the MI-PST group than in the MI and CG groups (adjusted mean difference of  $-1.72$ , 95 % CI  $-3.36 - -0.08$ ). There was no significant difference in these scores between the CG and MI groups (adjusted mean difference of  $-0.02$ , 95 % CI  $-2.01 - 1.96$ ). Brief interventions therefore appeared to be feasible for use in the emergency departments of a low resourced country. MI-PST was an effective brief intervention for reducing substance use among at-risk participants.

Tomlinson et al found 35% of mothers had increased antenatal depressed mood, similar across conditions. Being a mother, living with HIV, alcohol use, and food insecurity contributed significantly to antenatal depression. There were similar overall 18-month cognitive and motor scale scores on the Bayley Scales of Development. However, less children of intervention mothers diagnosed with antenatal depression were found to have below normal cognitive scores, compared to the children of standard care mothers assessed as having antenatal depressed mood. The children of mothers in the intervention were significantly more likely to have a better nutritional status (Weight-for-Age Z-scores  $<-2$ ). This study demonstrated that cognitive development and child growth can be improved by mentor mother home visitors, and may result in better parenting child care early in life.

Participants in the structured protocol arm of the Wagner study were more likely receive further medical evaluation using the PHQ-9 (84% vs. 49%; beta = 0.33; p = 0.01) (Wagner et al., 2016). Amongst clinically depressed clients (n = 369), there was no statistically significant advantage of the structured protocol over the clinical acumen model, in terms of the PHQ-9 depression

evaluation (93% vs. 68%;  $\beta = .21$ ;  $p = .14$ ), or the prescription of antidepressant medication (69% vs. 58%;  $\beta = .10$ ;  $p = .50$ ). The authors explained that this was partly due to the fact that only 30% of clients who screened positive turned out to be clinically depressed. Depression care practices were therefore widely adopted by health care providers, and depression care successfully reached most of the depressed clients. The study demonstrates that both models perform well in the background supportive supervision.

## **2.4 Discussion**

### **2.4.1 Summary of evidence**

Fifteen studies were included in this review, 14 of which focused on common mental disorders. Seven of the included trials were RCTs while 8 were non-randomized. Non-specialist roles included screening, intervention delivery, and collection of study measures. Interventions were acceptable and feasible and resulted in improved outcomes for mental health service users.

The focus of non-specialist worker intervention research remains on common mental disorders. This is not surprising as this group of disorders result in significant burden on individuals and the economy. Depression is the largest contributor to global disability (7.5% YLD), with anxiety disorders being ranked 6<sup>th</sup> (3.4% YLD), and both groups of disorders commonly co-occurring (World Health Organization, 2017a). Further work is however is needed on severe mental illness.

Nearly half of the studies included in this review were RCTs. While RCTs which can be conducted in real clinical settings remain the methodological gold standard (Essock, Drake, Frank, & McGuire, 2003), cost and resource limitations are often a hindrance to the employment of RCT design. Mental health research has historically been underfunded in Africa; a reality which has changed recently due to the recognition of mental and neurological disorders to the burden of disease and the existence of new funding models focused on non-specialist care models and research training in LMIC (Collins et al., 2011). The need for translation of research findings presents

an argument for a wide range of study design (Essock, Drake, Frank, & McGuire, 2003; Machado-Vieira, 2012). The acceptability and feasibility data reported by some of the included trials points to an awareness of the importance of this data in the negotiation of reprioritization of these types of interventions in such settings.

Non-specialist worker roles included participant recruitment and screening activities, as well as intervention delivery. This reflects previously identified roles of non-specialist workers, which tend to vary as determined by the education level of cadres (van Ginneken et al., 2013a). In some cases non specialist workers were also involved in outcome assessment. The impact of this role on assessment blinding is worth keeping in mind, as such roles are probably best played by independent staff not involved in delivering the intervention or data analysis and interpretation.

All of the included trials evaluating acceptability found that such interventions were acceptable and feasible, with socioeconomic factors having been identified in one trial to impact negatively on acceptability (Brooke-Sumner, Lund, Selohilwe, & Petersen, 2017). While acceptability findings are less specifically detailed in the other trials evaluating this, the trials in this review accessed available, willing and motivated local lay members of the community and primary health care services. Such community embeddedness has been identified as a contributing factor to the success of task shifting interventions (C. Campbell & Scott, 2011). These findings support the view of WHO that: “However, if task shifting is to improve the overall quality of care there must be agreed standards governing the recruitment and training of the new types of health workers that are established under the model and ensuring that existing health workers are appropriately qualified for the new tasks they will be asked to undertake. These standards involve defining the training and experience needed for each type of health worker, establishing examination and mentoring procedures and ensuring that there are opportunities for continuing education” (World Health Organization, 2007b). The training and supervision of the non-specialist workers are generally fairly well described, with some detailing ongoing specific ongoing approaches to fidelity assessments,

observation and supportive retraining. This in line with previously identified factors which contribute to acceptability and feasibility, which specifically include the availability of human resources with improved access to pharmacological treatments; effective supervision of staff at the level of the community and primary-care; and sufficient training and remuneration of task shifting cadres (Mendenhall et al., 2014). Some studies specifically focussed on providing personal supervision to the non-specialist workers. Together with the intervention training, this kind of component serves to address some other factors identified as barriers to task shifting, which include the possibility of reduced quality of care, burnout among non-professionals who may endure similar social stressors as the patients, and confidentiality (Dambisya & Matinhure, 2012; Inge Petersen, Ssebunnya, Bhana, & Baillie, 2011). One major factor which was seen as impacting negatively on feasibility was the absence of a component in an intervention which could lead to income generation (Brooke-Sumner et al., 2015), pointing to the financial need abound in such communities (Lepiéce, Reynaert, Jacques, & Zdanowicz, 2015; Lund et al., 2010; World Health Organization, 2012).

Included trials found outcomes in favour of the intervention. Post-intervention improvement in depressive symptoms was noted in 10 studies, while 1 showed improvement in PTSD symptoms and 1 demonstrated improvement in common mental disorders. One intervention successfully reduced risky substance use in at-risk individuals while another demonstrated improved mental health resulting from social cohesion following a psychosocial intervention. Findings that psychotherapeutic interventions may be effective are consistent with a broad range of previous literature (Lovelock, Mathews, & Murphy, 2010; van Ginneken et al., 2013a). Similarly, intervention employing measurement-based care have been found to result in improved outcomes for health service users while being acceptable and feasible (Fortney et al., 2017). The success of these interventions have been linked with regular and timely review of MHSU symptoms and adverse events, while single contact and the absence of routinely scheduled review of MHSU outcomes have contributed to ineffectiveness, as has inappropriate reporting of MHSU events outside of the therapeutic encounter, where there are relevant to subsequent treatment decisions. While none of

the trials included here looked at cost efficiency outcomes, this is a key aspect for translation of clinical research into clinical practice. Further work is therefore needed on the cost-efficiency of task-shifting interventions for psychiatric disorders. In an exploration of human resource requirements and costs for rural settings, the minimal cost of a task shifting approach was found to be offset by a reduction in the number of specialist and non-specialist health personnel required to close the service gaps (Inge Petersen, Lund, Bhana, Flisher, & Consortium, 2012). In their stepped-care programme for the primary-care management of depression it was noted that task shifting was only marginally more expensive than treatment as usual (Araya, Flynn, Rojas, Fritsch, & Simon, 2006). An investigation into the cost-utility of behavioural activation delivered by the non-specialist found that behavioural activation potentially offers lower cost per quality adjusted life year (QALY) or point reduction on the BDI-II than brief problem-solving or online CBT interventions also aimed at increasing accessibility (Ekers et al., 2011). These findings however focus on observed differences over 3 months and make no assumptions regarding maintenance of longer-term treatment-related improvement, with small sample sizes limiting the precision and generalizability of findings.

Further research is required to explore fully the effect of task shifting interventions on patient health outcomes, quality of care and costs (Fulton et al., 2011). The WHO has proposed that task shifting must be implemented within systems that contain adequate checks and balances to protect both health workers and the people receiving treatment and care (World Health Organization, 2007). Other factors that may affect outcomes include the extent of management, appropriate patient selection, suitable training, adequate retention structures and good relationships with other healthcare workers (Campbell & Scott, 2011).

#### **2.4.2 Limitations**

One major limitation is that the review did not include unpublished studies. The number of trials in Sub Saharan Africa was limited, and used heterogenous methodologies, and non-

comparable scales. The second limitation therefore, was that a meta-analysis could not therefore be undertaken. This limits the ability of this review to establish an impression of pooled efficacy. An extension of this review in future may include a meta-analysis.

### **2.4.3 Conclusions**

There is an evidence base that supports task shifting to non-specialist health workers as a potential way of addressing the treatment gap in psychiatric service delivery, in resource strapped LMIC such as those in Sub-Saharan Africa. The studies reviewed here all showed results favouring task shifting interventions, in the context of well-described training and supervision of the non-specialist workers. The findings must be interpreted with caution however, as the cadres recruited to administer these interventions may not represent the reality non-specialist workers are confronted with in their day to day work. Non-specialist cadres often have a host of additional responsibilities, which may impact on the acceptability and feasibility of such interventions. That being said, there may be potential for such treatment programs developed in LMIC to provide useful models for mental health care in better-resourced countries. Elements of concern to participants, including a need for the inclusion of poverty-alleviation elements in community-based interventions need to be borne in mind. While it may not be in the scope of many envisaged interventions to directly address this need, the impact on intervention acceptability and feasibility should be taken into consideration during intervention conceptualization and design.

Nevertheless, the evidence base remains small, and there are several reasons for caution at this stage. Future research is needed on the long-term efficacy of task shifting interventions, to explore the impact of such service delivery on lay health workers and communities, and to determine the optimal indications for and contexts supporting task shifting.

## **Chapter 3 Pilot randomized controlled trial: Task shifting and m-health intervention vs. treatment as usual**

In the systematic review in Chapter 2 only 1 study focused on severe mental illness. Severe mental illness presents a significant burden on individuals and services in our setting. This chapter expands on this background, and describe the processes and findings of a task shifting intervention aimed at supporting adherence for severe mental illness.

### **3.1 Background**

Treatment partner interventions may represent a particularly useful task-shifting approach in adherence-promotion for mental health. One such approach uses mental health service users (MHSUs) as peer supports (Davidson, Chinman, Sells, & Rowe, 2006). In addition to substituting for regular workers, peers may offer key contributions such as providing unique insight into experiences that may be shared by MHSUs (Sells, Black, Davidson, & Rowe, 2008). In Chapter 1, some of the factors that contribute to the increased burden for families and caregivers of MHSU were presented. There are however few studies that explore the factors impacting an effective caregiving relationship from the perspective of MHSUs and their caregivers, particularly in the context of supporting adherence in our local setting.

Approaches to adherence-support have thus emphasized the importance of health literacy, problem-solving, and social support, as well as the potential of telephone prompts (Haynes et al., 2008; Nosé et al., 2003). M-health approaches such as telephone prompts close to the time of the local clinic visit appointment have previously shown promising results in encouraging adherence and clinic attendance, as has an orientation type letter on discharge (Nosé et al., 2003; Rowett, Reda, & Makhoul, 2010). To date this technology has not been widely used in interventions aimed at improving adherence to treatment by MHSUs with severe mental illness in LMIC.



An approach that draws on recent innovations in mobile technology can potentially integrate task shifting, psychoeducation and m-health approaches in order to facilitate a comprehensive intervention for addressing adherence that is appropriate and feasible in a developing country. It is however not clear whether an approach incorporating these components is feasible in a LMIC setting, such as South Africa.

The aim was to test the acceptability and feasibility of a treatment partner, psychoeducation and text message intervention in supporting adherence in people with severe mental illness. The primary outcomes were the acceptability and feasibility of the intervention, while efficacy outcomes which were secondary, included adherence to first clinic visit; relapse, measured by any readmission in the 9 months following recruitment; quality of life; symptomatic relief and medication adherence. The efficacy outcomes of the intervention were compared with treatment as usual (TAU). Further, the factors impacting caregiving as experienced by both treatment partners who participated in the intervention, and caregivers from the treatment as usual group were explored. The views of the MHSU from both arms of the study were drawn, eliciting their experience of the support they received from their caregivers.

## **3.2 Methods:**

### **3.2.1 Study design**

For acceptability and feasibility outcomes a qualitative study design was adopted in the form of semi-structured interviews. Additional feasibility assessment was obtained from review of fieldworker interaction with the mobile health component. In order to measure efficacy outcomes, a two-arm non-blinded prospective pilot randomized controlled trial (RCT) was conducted. The RCT design is ideal for clinical settings, and allows for the manipulation of certain conditions while controlling for others. The findings from this study design are more likely to yield a link suggesting causality through randomization and the use of a control group for comparison.

### **3.2.2 Ethics and registration**

The study was registered with the Pan African Clinical Trials Registry (PACTR201610001830190) and approved by the Human Research Ethics Committee, Faculty of Health Sciences, University of Cape Town (HREC REF: 511/2011). Institutional approval was obtained from the Western Cape Department of Health Impact Assessment Unit (RP168/2011). All participants signed informed consent prior to any study procedures and received a handout containing study information detailing the study processes, informed consent and confidentiality. Anonymity of participants was protected by the use of study IDs, with the corresponding identifying list being stored separately and securely. No monetary incentives were provided for participation in the study. Participants were however reimbursed for travel expenses where required, for review appointments.

### **3.2.3 Study setting**

Valkenberg Hospital is located in Observatory, Cape Town and is one of 4 referral hospitals providing specialist psychiatric in the Western Cape (Western Cape Government, 2017b). It is the main teaching hospital for the University of Cape Town's Department of Psychiatry and Mental Health (University of Cape Town Department of Psychiatry and Mental Health, 2017), providing in- and outpatient specialist psychiatric services for mental health service users (MHSU) from the Southern, Western and Klipfontein sub-districts of the Cape Town metro (See Figure 4-1), as well as the Eden and Central Karoo rural districts (See Figure 3-1) which refer to Valkenberg via George Hospital (Western Cape Government, 2017a). The hospital has 116 male, and 84 female inpatient beds with an average length of stay of 39 days. MHSU admitted at VBH have diagnoses of schizophrenia (32,4%); schizoaffective disorder (15,5%); bipolar mood disorder (22,1%) and substance induced mood disorder 17,3%). Severe mental illness therefore constitutes a significant burden on services and disability.

**Figure 3-1 Western Cape Province Health Districts**



Source: [https://commons.wikimedia.org/wiki/File:Map\\_of\\_the\\_Western\\_Cape\\_with\\_municipalities\\_labelled\\_\(2006\).svg](https://commons.wikimedia.org/wiki/File:Map_of_the_Western_Cape_with_municipalities_labelled_(2006).svg)

The catchment area of Valkenberg Hospital is serviced by psychiatry clinics located within several Community Health Centres (CHCs) in the Cape Town metro, which provide primary health services to surrounding communities. These psychiatry clinics are operated by mental health nurses who 1) receive MHSUs discharged from inpatient psychiatric care; 2) provide clinical and psychosocial review of these MHSUs; 3) renew and top up medication; 4) schedule follow up clinic visits, and 5) receive acutely relapsing MHSUs for assessment to either manage or refer for specialist assessment. The mental health nurses are supported by rotating psychiatric registrars to whom they are able to refer through a booking system, more complex MHSU as required. The mental health nurses receive routine clinical support and ongoing training from a specialist psychiatrist at Valkenberg Hospital.

Psychosocial rehabilitation and support services for MHSU and their families/immediate support networks are provided by non-profit community-based organizations. These include organization such as Friends of Valkenberg, Cape Mental Health, Cape Support for Mental Health and COMCARE.

### **3.2.4 Selection of participants**

Adult MHSU were recruited, who had been admitted to Valkenberg Hospital with a diagnosis of a severe mental illness, and were about to be discharged following an admission for an acute illness episode. Inpatient clinical folders of MHSU in the pre-discharge wards were screened for potential participants. Some potential participants were referred by their treating clinical team. Included MHSU had: a) A diagnosis of schizophrenia spectrum disorder including schizophrenia, schizoaffective disorder, schizophreniform disorder; b) A diagnosis of psychotic disorder not otherwise specified; or c) Substance Induced Psychotic Disorder; or d) A diagnosis of a Bipolar Mood Disorder Type I. To be eligible, participants had to have either their own mobile phones, or have easy access to text messages through the mobile phone of a friend or family member. Eligible MHSU were approached and informed consent obtained from those willing to participate after being informed about the study. Exclusion criteria included: a) A diagnosis of a psychotic disorder due to a general medical condition, dementia, moderate to severe intellectual disability; or b) Suicidality or homicidality; or c) an inability to give informed consent.

### **3.2.5 Randomization**

Consented MHSU were randomized to receive either the intervention or treatment as usual (TAU), using a randomization sequence generated by an external statistician. Allocation concealment was ensured by using opaque, sealed sequentially numbered envelopes. Once a participant had completed baseline measures, a UCT secretary who was not involved in the study

was contacted telephonically. She would then open a sealed envelope and read out the allocation contained within the envelope. The opened envelope was then discarded. Study staff did not come into contact with these envelopes. Due to the nature of the intervention, it was not possible to blind participants and study staff to the outcome of randomization.

### **3.2.6 Routine Care/Treatment as Usual**

In routine care, once stabilized following an acute admission, MHSU are discharged from VBH's pre-discharge wards for follow up at the psychiatry clinic closest to their place of residence. MHSU are discharged, following a routine non-standardized pre-discharge psychoeducation session, with a referral letter containing the details of their inpatient treatment and their discharge prescription. MHSU are given a 4-week supply of medication and instructed to present themselves as soon as possible after discharge to their local CHC with the referral letter to schedule a review date with the facility's mental health nurse. In cases where a depot injectable antipsychotic is part of the treatment regimen, this appointment generally coincides with the due date of the next depot injectable dose. On presenting at the clinic on the scheduled follow up date, MHSU are recorded on the facility's attendance roster, reviewed by a mental health nurse or a psychiatric registrar, receive a top-up of their medication and are then given a further follow-up appointment date. For the purposes of this study routine care with no enhancement constituted treatment as usual (TAU).

### **3.2.7 Treatment partner and text message intervention**

The 3-month intervention incorporated TAU with the addition of 1) a single treatment partner contracting and psychoeducation session and 2) monthly text message reminders for post-discharge clinic appointments.

#### **3.2.7.1 Intervention development**

I and my colleagues undertook a formative qualitative study to inform the design of the intervention (Mall et al., 2013). We conducted focus groups and semi-structured interviews to obtain the views of MHSU and their caregivers about the desirable features of a treatment partner and mobile health intervention. Focus groups allow for a deeper exploration of the respondents' views and opinions, while the semi-structured interviews shed light on respondents' needs, attitudes and insights (Harper & McCunn, 2017). Combining the two methods allowed us to triangulate the data, which is useful in generating different perspectives of the research question (Ritchie & Spencer, 1994).

In developing the interview guides for the focus groups and in-depth interviews, I and my colleagues searched the literature for studies which featured the inclusion of MHSU and caregivers in relation to psychiatric illness, as well as more general adherence-focused studies conducted in South Africa. The search of general studies retrieved mostly studies of adherence in HIV/AIDS and Tuberculosis. The interview guides were then developed for the different categories of participants (i.e. MHSU and caregivers), incorporating issues that emerged from the literature search. The interview guide probed participants' understanding of mental illness and their specific diagnosis, adherence-related issues and more specific characteristics of what should comprise the treatment partner relationship and intervention.

This investigation was conducted at Valkenberg Hospital. Purposive sampling was used for the recruitment of the sample. For the MHSU groups we included those with a diagnosis of schizophrenia, bipolar mood disorder and schizoaffective disorder. The caregiver group was comprised of the mothers of MHSU fitting the same profile. Mothers were recruited as they were present on the day of study activities. I and my colleagues, with the assistance of nursing staff, approached MHSU who were awaiting discharge in the pre-discharge ward or who were attending the hospital's outpatients' department. The caregiver group was recruited with the help of a clinical psychologist at the hospital, who is familiar with this population.

Four separate focus groups were held, comprising: 1) Six MHSU who had received inpatient treatment during the preceding 5 years, and who had remained discharged for longer than a year. 2) Seven people who were family members or close friends of MHSU who had received inpatient treatment during the preceding 5 years, and who had remained discharged for longer than a year; 3) Eight male MHSU in the pre-discharge ward of Valkenberg Hospital; and 4) Six female MHSU in the pre-discharge ward of Valkenberg Hospital. In addition, individual semi-structured in-depth interviews were held with 6 MHSU (3 male, 3 female) who were about to be discharged from inpatient treatment at the hospital and 4 MHSU (2 male, 2 female) presenting at VBH OPD for routine outpatient clinical follow-up.

Focus group and in-depth semi-structured interviews were audio-recorded and transcribed by an independent transcription service in Cape Town. Thematic analysis was then conducted, which included the steps of: 1) familiarization with data; 2) identification of a thematic framework; 3) indexing; 4) charting; and 5) mapping and interpretation (Ritchie & Spencer, 1994). The ATLAS TI qualitative data software was used for the management and analysis of the data.

Themes that arose revolved around 1) current approaches to adherence; 2) suggestions for the ideal characteristics of a treatment partner; and 3) suggestions for the design of the intervention. Caregivers, who were generally mothers and close family members, tended to adopt an active approach to adherence support, and had naturally taken on the role of a treatment partner.

In spite of feeling wholly capable of self-monitoring their treatment, MHSU were receptive of adherence assistance from caregivers. MHSU were concerned that at times caregivers can become too controlling, and voiced a need for the caregiving relationship to be negotiated such that it did not compromise the MHSU's autonomy. Caregivers voiced the importance of empathy and compassion in their role, and all participants felt that a treatment partner would be a good approach

to adherence-support. MHSU and caregivers agreed that this support should include medication adherence as well clinic visit adherence.

Participants voiced a need for more psychoeducation about their diagnosis and treatment. They wanted to understand more clearly the processes that take place after discharge and when readmission was required. Both MHSUs and caregivers felt that the text message reminders would be best sent as often as medication needed to be taken.

This qualitative component was useful in informing the final design of the RCT. It was clear that a treatment partner relationship had to be negotiated and individualized, with both parties agreeing to the terms of the relationship. This was called the treatment partner contract. A psychoeducation component was designed in line with the needs expressed. Text message reminders received support as an adherence support tool.

### **3.2.7.2 Intervention description**

#### ***Treatment partner***

The treatment partner, who had to have access to text messages via his or her own mobile phone or the mobile phone of a family member, was selected by the participant randomized to receive the intervention. This could be anyone with whom the MHSU had an existing relationship, ranging from friends to family, and whom the MHSU felt could reliably function as an adherence support person. I contacted the nominated treatment partner telephonically to explain study objectives and procedures and asked whether he or she would be willing to act in this role. If the nominated treatment partner were unwilling or unable to participate, the participant would nominate an alternative potential treatment partner until a nominee agreed to participate. This treatment partner was invited to an appointment at a convenient date soon thereafter, while the patient was awaiting discharge from inpatient care. The intervention procedures were initiated at this appointment and began with treatment partner contracting.



Treatment partner contracting began with an appraisal of the existing caregiving relationship between the participant and their elected treatment partner. This included exploration of the style of day-to-day interaction as well as existing caregiving and adherence support activities within the relationship. Based on this and in light of the preceding psychoeducation session, an individualized participant/treatment partner relationship was negotiated and agreed upon, detailing communication and general support strategies, as well adherence-support and response to signs of relapse. Both parties then signed a participant/treatment partner contract. Treatment partners were assured access to mental health care for participants, and advice via the psychiatry clinic at the CHCs.

### ***Psychoeducation***

Psychoeducation focused on the specific diagnosis of the participant and was based on the Western Cape Department of Health's HIV education programme and the Valkenberg Hospital psychoeducation guidelines. Consultant psychiatrists at Valkenberg Hospital reviewed and provided input into the psychoeducation guide. Psychoeducation took into account the mental health literacy needs expressed by MHSUs during the formative focus group work and included descriptions of symptoms, syndrome presentation, aetiology, management strategies, medication side effects, signs of relapse and the potential impact of substance use. It also detailed available community support resources for MHSUs and their families/support network. Information was provided on standard post-discharge care and adherence support, which included laying out clearly the clinical and psychosocial review processes that they could expect to encounter when presenting at a CHC to attend a psychiatry clinic for review or assessment.

### ***Text message reminders***

An automated text message system was set up to remind both the participant and the treatment partner in the intervention group of psychiatry clinic review appointment dates provided by the treating clinical team at the time of discharge from inpatient care. The system was developed

and hosted securely by a local software developer with extensive experience in m-health trials. One enrolment handset was programmed to load all participants (Intervention and TAU) and treatment partner (Intervention only) information upon routine discharge from Valkenberg Hospital. Information loaded onto the secure platform included the name of the participant and treatment partner to enable personalization of text messages; the CHC at which the review appointment had been booked; the date of the review appointment as issued by the treating clinical team; and the randomization to indicate for the system which participants would receive the text message reminders. Fifteen fieldworker handsets were programmed for use by the mental health nurses at the psychiatry clinics. Once participant information had been loaded onto the system via the enrolment handset, the fieldworker handsets were immediately remotely populated with the relevant participant information (name and appointment date) corresponding to the specific clinic to which the participant had been discharged. The information transfer was however not automatic due to cost constraints. The mental health nurses refreshed their handsets on a daily basis to ensure they had the most current participant schedule on their handsets. The fieldworker handsets provided a field for the participants to be marked as having attended their clinic appointment. After the completion of clinical review, the mental health nurse entered on the fieldworker handset, the date for the next clinical review, around 4 weeks later. The text message platform was updated immediately as handsets were refreshed, with resulting text message reminders being sent to intervention MHSU and treatment partners automatically from the platform. The platform developers provided detailed training to all staff that would be interacting with the platform, with refresher courses being made available as required.

### **3.2.8 Outcome measures**

Primary outcomes of interest were the acceptability and feasibility of the intervention. Efficacy outcomes, which were secondary, included adherence to first follow-up clinic visit; relapse, defined as readmission to any primary or referral hospital; medication adherence; quality of life and

symptomatic relief. The expectation was that all components of the intervention would be acceptable and feasible; and result in increased first clinic visits and reduced readmissions at 9 months. A further expectation was an improvement in medication adherence, quality of life, a reduction of needs and symptomatic improvement. See Figures 3-2 and 3-3 below.

**Figure 3-2 Outcomes measures and associated instruments**

<i><b>Outcome</b></i>	<i><b>Measure</b></i>	<i><b>Instrument</b></i>
Acceptability and feasibility outcomes	Acceptability and Feasibility of Intervention	Qualitative interview at 3 months.
Efficacy outcomes	Adherence to first clinic follow-up visit	Data collected via Community Health Centre using text message technology for intervention for 3 months and by retrospectively checking attendance register for both intervention and TAU
	Relapse (Any readmission)	Re-admissions noted via Clinicom
	Medication adherence	MARS <sup>1</sup>
	Quality of Life	EUROQUOL; CAN2
	Symptomatic Relief	CGI <sup>3</sup> , GAF <sup>4</sup> , PANSS <sup>5</sup>

<sup>1</sup>Medication Adherence Rating Scale; <sup>2</sup>Camberwell Assessment of Needs Scale <sup>3</sup>Clinical Global Impression Scale;

<sup>4</sup>Global Assessment of Function Scale; <sup>5</sup>Positive and Negative Syndrome Scale

### **3.2.8.1 Acceptability and feasibility measures**

Semi-structured interviews were conducted at 3 months post-discharge, with participants and their respective treatment partner for the intervention group and caregivers for the TAU group to draw acceptability and feasibility data. This interview was designed to specifically explore content presented during the psychoeducation and treatment partner-contracting component, and in the course of standard discharge psychoeducation for the TAU group. Participants were asked about their insights into their diagnosis and medication; their adherence behaviour; the standard pre-discharge psychoeducation they had received for the TAU group; the psychoeducation and contracting session for the intervention group; and about their experience of attending appointments at the CHC. Treatment partners were asked about their experience of, and challenges

faced in the intervention relationship; their perception of the clinic-visit experience; as well as their own feedback on components of the intervention. They provided feedback on the participant's medication and clinic visit adherence, and on the perceived value of such an intervention. Participants and caregivers in the TAU group provided feedback on their experience of the standard caregiving relationship. The interviews were conducted in the language preferred by the respondents, in the presence of a translator.

### **3.2.8.2 Efficacy measures**

#### ***Symptom severity***

All participants underwent a Structured Clinical Interview for Diagnosis of Axis-I Disorders (SCID-I) (First, Spitzer, Gibbon, & Williams, 2002) to characterize the nature of the study population diagnostically, which included a Global Assessment of Function Scale (GAF) (Hilsenroth et al., 2000) and Clinical Global Impressions scale (CGI) (Guy, 1976). Additionally, the Positive and Negative Syndrome Scale (PANSS) were administered as a measure of severity and structure of psychotic symptoms. These standard scales for diagnosing and assessing schizophrenia have been widely used in South Africa in both genetics studies and treatment studies (Emsley, Rabinowitz, & Medori, 2007; Emsley et al., 2008; Emsley, Nuamah, Hough, & Gopal, 2012; Roos, 2011; Spies et al., 2009).

#### ***Quality of life and medication adherence***

Needs were measured using The Camberwell Assessment of Needs Scale (CAN), which has been validated for the assessment of needs of people with severe mental illness (Phelan et al., 1995) as well as for use in our local population (Flisher, Sorsdahl, & Joska, 2012). The EUROQOL was used as a measure of quality of life (EuroQol Group, 1990). The scale which looks at 5 dimensions: mobility; self-care; usual activities; pain/discomfort; and anxiety/depression, includes a Visual Analogue Scale (VAS), which allows the respondent to score his or her subjective well-being on a continuous scale of 0-100%, has been used widely in schizophrenia research studies (Karow,

Wittmann, Schöttle, Schäfer, & Lambert, 2014). The Medication Adherence Rating Scale (MARS) (Fialko et al., 2008) was used as a measure of medication adherence behaviour. This scale is useful in chronic mental illnesses and was specifically designed with a focus on schizophrenia, eliciting barriers to and beliefs about medication adherence (Lam & Fresco, 2015).

### ***Clinic attendance and readmission***

The text message platform was used to follow up intervention group attendance at first clinic visit. The attendance of the entire group, including both intervention and TAU groups was additionally captured retrospectively by assessing the physical attendance registers at the clinic at the end of the intervention. Any re-admissions were noted via Clinicom, a secure online platform used to monitor the movement of all health service users in Cape Town. All health service users making use of inpatient and outpatient hospital services in the Cape Town metropole are tracked on this platform. Detailed notes are maintained regarding assessments, test results, admissions, transfers and treatment plans. Only authorized health care practitioners are provided access to these records.

### **3.2.9 Study Procedures**

Recruitment was conducted during the two-year period from 1 June 2012 to 31 May 2014. Study procedures are represented in Figure 3-4 alongside stages of routine care and corresponding timelines. Consented MHSU underwent baseline assessments, including the SCID, GAF, CGI, MARS, CAN, PANSS and EUROQUOL. Once baseline assessments were completed, participants were randomized as described above. For the intervention group, treatment partner contracting and psychoeducation were then conducted at Valkenberg Hospital on the date arranged with the selected treatment partner.

Participating MHSU were discharged as per routine hospital discharge protocol, for routine post-discharge care. All participants were loaded onto the automated text message platform

immediately upon routine discharge from inpatient care. A text message notification was then automatically sent to the participant and treatment partner in the intervention group, noting the name of the participant and the review appointment clinic and date. Another text message reminder was sent one week prior to the appointment date. The mental health nurses, having refreshed their handsets, would then know which participant was coming in for review and on which date. When the participant arrived at the clinic the mental health nurse marked the participant as having attended. The nurse would then schedule a follow up appointment on the system, which would then send similar reminders to those sent upon initial discharge from the hospital. The nurses were to schedule two follow up appointments in total using the fieldworker handsets, which meant the system carried the notifications of three visits altogether.

**Figure 3-3 Time frames and associated instruments**

Initiation	3 Month Follow Up	9 month
1. Participant selection as per inclusion criteria		
2. Randomisation	1. Qualitative review:	
3. Consent and contract	a. MHSU perspective,	
4. Baseline instruments	b. Treatment partner or carer perspective.	Determine and record re-admissions via Clinicom
SCID <sup>1</sup>	2. Review appointment adherence	
CGI <sup>2</sup>	3. Determine and record re-admissions via Clinicom	
GAF <sup>3</sup>	4. Efficacy measures	
MARS <sup>4</sup>	a. MARS, CGI, GAF, PANSS, CAN and EUROQOL	
CANS <sup>4</sup>		
PANSS <sup>6</sup>		
EUROQUOL		

All participants were then expected to present for a follow up study visit at the end of the intervention, 3-months from discharge and enrolment. The GAF, CGI, MARS, PANSS, CAN and EUROQUOL were re-administered at this visit. Additionally, during this visit, the semi-structured interviews were conducted as described above. These were audio-recorded and transcribed before

undergoing thematic analysis. At 9 months after discharge from inpatient care, any readmissions for were noted using Clinicom.

**Figure 3-4 Routine care timelines and corresponding study activities**

Stage in MHSU care	MHSU care activity	Corresponding research activity	
	Routine Care	Treatment as Usual = Routine Care PLUS	Intervention = Treatment as Usual PLUS
<b>In pre-discharge ward</b>	<p>The MHSU receives standard pre-discharge care. This includes</p> <ul style="list-style-type: none"> <li>• Clinical review</li> <li>• Finalizing of treatment plan</li> <li>• Psychosocial rehabilitation programmes</li> <li>• Individual and group psychoeducation</li> <li>• Discharge planning by the clinical team, encompassing identification of which CHC the MHSU will be discharged to and when, as well as arrangement of post-discharge psychosocial support for the MHSU.</li> </ul>	<ol style="list-style-type: none"> <li>1. Informed consent was obtained from eligible patients.</li> <li>2. Recruitment activities including diagnostic and baseline measures were conducted as described in the text.</li> <li>3. Recruited participants were randomized to receive either treatment as usual or the intervention.</li> <li>4. Participants were informed which group they had been randomized to.</li> </ol>	<ol style="list-style-type: none"> <li>5. Participants who had been randomized to receive the intervention selected a treatment partner as described in the text.</li> <li>6. These selected treatment partners were contacted telephonically, consented and a date was set for the psychoeducation and contracting session.</li> <li>7. The psychoeducation and contracting session was conducted at Valkenberg Hospital for the participant and treatment partner pair.</li> </ol>
<b>On day of discharge</b>	<p>The MHSU discharged from inpatient care with referral letter detailing course of admission, diagnosis, treatment plan, review CHC and date.</p>	<ol style="list-style-type: none"> <li>8. Participants were enrolled onto the text message platform.</li> </ol>	<ol style="list-style-type: none"> <li>9. The first text message was sent to the participant/ treatment partner pair containing details of first clinic appointment as per discharge treatment plan.</li> <li>10. Fieldworker handsets received updated participant review schedules.</li> </ol>
<b>One week before first clinic appointment.</b>	No activity	No activity	<ol style="list-style-type: none"> <li>11. A text message reminder was sent to the participant/treatment partner pair containing same details as first message.</li> </ol>
<b>At First clinic appointment</b>	<p>The MHSU is reviewed by the mental health nurse or psychiatry registrar at the psychiatry clinic of CHC.</p> <p>Medication is renewed or modified.</p> <p>A follow up appointment is issued.</p> <p>The MHSU's CHC clinical record clinical record updated to indicate:</p> <ul style="list-style-type: none"> <li>• Attendance for review</li> <li>• Clinical status</li> <li>• Medication review and prescription</li> <li>• Next scheduled appointment date</li> </ul> <p>The MHSU collects his or her medication and leaves the CHC.</p>	No additional activity	<ol style="list-style-type: none"> <li>12. On arrival, mental health nurse checks the participant as present.</li> <li>13. The mental health nurse asks the participant how many days of medication have been missed since discharge from hospital and enters this information on the fieldworker handset.</li> <li>14. The mental health nurse enters the next scheduled clinic review appointment date onto the text message platform via the fieldworker handset.</li> <li>15. The participant/treatment partner pair immediately received a text message notification indicating the next appointment date with the name of the CHC as in the initial text message.</li> </ol>
<b>After the First Clinic appointment</b>	<p>The MHSU is reviewed on the scheduled review date and the process described above at first clinic appointment is repeated for subsequent visits.</p>	No additional activity.	<ol style="list-style-type: none"> <li>16. The participant/treatment partner pair receives a text message reminder of the next appointment date one week before that appointment.</li> <li>17. The process described at steps 12-16 above is repeated for three visits in total.</li> </ol>
<b>Three Months after discharge</b>	Routine clinical care is continued.	<ol style="list-style-type: none"> <li>18. All participants, accompanied by their caregivers for the TAU group or treatment partners for the intervention group, returned at 3 months after discharge for clinical and review and qualitative interviews as described in the text.</li> </ol>	
<b>Nine months after discharge</b>		<ol style="list-style-type: none"> <li>19. Any readmissions were noted for all participants were noted via Clinicom.</li> </ol>	

Numerical order indicates the flow of study activities.

Figure is reproduced from Sibeko et al. BMC Res Notes (2017) 10:584 (Goodman Sibeko et al., 2017)



### **3.2.10 Statistical Analysis**

#### **3.2.10.1 Quantitative data**

For the clinic attendance and relapse outcomes, the distribution of variables was explored using histograms, boxplots and the Shapiro-Wilk test for normality. Any non-normally distributed variables were transformed where possible, using a logarithmic transformation. Exploratory analyses of normally distributed data were carried out using student's t-test, and for non-normally distributed data, Wilcoxon rank-sum tests were used. Categorical data were analysed using Chi-square tests with Fisher's exact test where appropriate. For the analyses of the rest of the efficacy outcomes generalized linear regression modelling was used to adjust for baseline covariates that were of theoretical prognostic importance and both unadjusted and adjusted analyses are reported. For all these outcomes both complete-case and intention to treat analyses are reported, thereby including data on all randomized participants in analyses. As single imputation methods such as last observation carried forward methods (LOCF) can introduce bias, multiple imputation was used to account for missing data. The missing at random pattern (MAR) was confirmed using logistic regression analyses. A multiple imputation with chained equations (MICE) approach using the Stata mi suite of commands was used to construct imputation models. Auxiliary variables were added to the imputation models based on significant associations or strong correlations of potential auxiliary variables with missingness or missing variables. For clinic visit attendance and relapse outcomes, missing baseline variables were imputed by creating a set of 25 imputation models and for other efficacy outcomes, 50 imputation models on which the final analysis models were fitted. Effect estimates and standard errors were then pooled. As missingness for some secondary outcome variables were very high (up to 75% for some variables), only imputation analyses were conducted for variables that did not exceed 55% missingness (PANSS scores and MARS scores). Linear regression models were checked for normality of residuals and heteroscedasticity. All effect

measures are reported as risk ratios or mean differences with their corresponding 95% confidence intervals. A two-tailed significance level of 5% was used throughout and analyses were conducted using Stata version 13.

### **3.2.10.2 Qualitative data**

The 3-month semi-structured interviews were transcribed by an independent transcription service in Cape Town and reviewed to gain familiarity with the data and develop a coding process. Intervention pair interviews were reviewed and analysed together, followed by a framework analysis consisting of the following steps 1) Identifying key emergent themes and developing a thematic framework. 2) Drawing relationships between the different themes; 3) Mapping and interpretation (descriptions of the findings); particularly in relation to the ethic of care framework and the usefulness of the intervention for people with severe mental illness. A qualitative analysis programme (NVIVO 8) was used to manage and analyse the data.

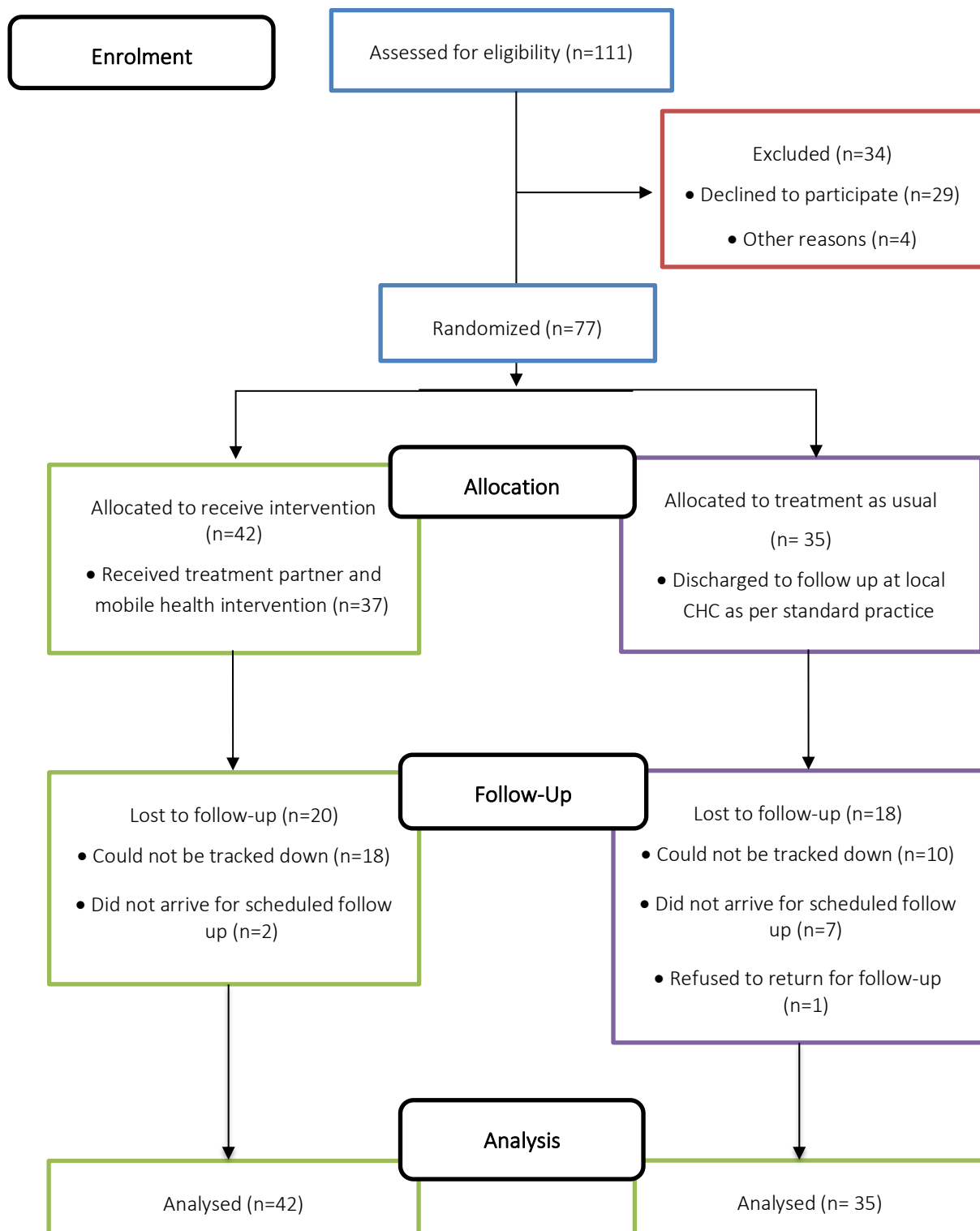
## **3.3 Results**

### **3.3.1 Participants**

Figure 3-4 below shows the flow of participants in this study. Seventy-seven participants were recruited during the 2-year period. Forty-two (54.5%) were randomized to the Intervention arm and 35 (45.5%) to the TAU arm. In the intervention arm 4 participants withdrew at baseline. There were no participant withdrawals at baseline amongst the TAU group. Thirty-Seven Participants in the intervention group received the intervention and were enrolled onto the text message platform. Seventeen participants each, from both arms of the study completed the full 3-month review. Two (5.8%) participants from the intervention did not arrive for a scheduled 3-month review appointment vs. 7 (2.0%) from the TAU group. I was unable to schedule 18 (42.9%) 3-month reviews in the intervention group vs. 10 (28.6%) in the TAU group. This was largely due to

untraceable participants, either as a consequence of changed or lost mobile phone numbers or a reluctance to continue to engage with the project.

**Figure 3-5 CONSORT flow chart for the study**



The demographic characteristics of the sample are presented in Table 3-1 below. At baseline the sample (n=77) with a mean (SD) age of 35.5 (10.2) consisted of 55 males (71.4%) with a mean age of 34.12 (10.2) and 22 females (28.6%) with a mean age of 40.80 (8.99). Most (67.5%) of the participants had never been married, while 20 were either currently or previously married. Thirty-two (41.6%) of the participants were Afrikaans-speaking, while 23 (29.9%) were English speaking and 16 (20.8%) were Xhosa speaking, reflecting the demographics of the local population (Statistics South Africa, 2011). The majority of the participants (69.1%) were unemployed in the 6 months preceding recruitment into the study, compared with 48.1% in the 3 years preceding recruitment. Thirty-four (44.2%) of the participants, of whom 29 were male, were receiving social assistance in the form of a disability grant for mental illness at the time of recruitment.

Thirty-nine (50.6%) participants met diagnostic criteria for schizophrenia, 13 (16.9%) met criteria for schizoaffective disorder, 11 (14.3%) for bipolar mood disorder, 7 for psychotic disorder not otherwise specified, 4 (5.2%) for substance induced psychotic disorder and 3 (3.9%) for schizophreniform disorder. Thirty-one (40.3%) participants met criteria for lifetime diagnosis of substance use disorder. There was no significant difference between participants who were successfully followed up and those lost to follow up.

**Table 3-1 Baseline Variables**

	Total sample <sup>1</sup> (N=77)		Intervention (N=42)		TAU (N=35)		Statistic(df)	p-value
Participant characteristics	mean	(SD)	mean	(SD)	mean	(SD)		
Age	35.5	(10.2)	35.3	10.9	35.8	9.5	t= -0.35(75)	0.726
	<b>N</b>	<b>(%)</b>	<b>N</b>	<b>(%)</b>	<b>N</b>	<b>(%)</b>		
Sex							$\chi^2= 1.03(1)$	0.311
Male	55	71.4	28	66.6	27	77.1		
Female	22	28.6	14	33.3	8	22.9		
Ethnicity							$\chi^2= 0.51(2)$	0.774
Coloured	47	66.2	26	66.7	21	65.6		
Black	18	25.3	9	23.1	9	23.1		
Other	6	8.5	4	10.3	2	6.3		
Marital status							$\chi^2= 0.29(1)$	0.591
Never married	51	71.8	27	69.2	24	75.0		
Ever married	20	28.2	12	30.8	8	25.0		
Highest Level of Education							$\chi^2= 0.15(2)$	0.930
Grade 7 or less	12	17.7	6	16.7	6	18.7		
Grades 8 to 11	42	61.8	22	61.1	20	62.5		
Grade 12	14	20.6	8	22.2	6	18.8		
6 Month employment							$\chi^2= 0.31(1)$	0.579
Unemployed	47	69.1	28	71.8	19	65.5		
Employed	21	30.9	11	28.2	10	34.5		
Diagnosis								0.604
Schizophrenia Spectrum	62	80.5	32	76.2	30	85.7		
Bipolar mood disorder	11	14.3	7	16.7	4	11.4		
Substance Induced Psychotic Disorder	4	5.2	3	7.1	1	2.9		
Substance use							$\chi^2= 0.18(1)$	0.671
Lifetime Substance Use Disorder	31	40.3	16	38.1	15	42.9		
Antipsychotic								
First generation	50	64.9	26	61.9	24	68.6	$\chi^2=0.37(1)$	0.542
Second generation	19	24.7	12	28.6	7	20.0	$\chi^2= 0.75(1)$	0.385
Long acting injectable	22	28.6	10	23.8	12	34.29	$\chi^2= 1.03(1)$	0.311
<b>Baseline measures</b>	<b>mean</b>	<b>(SD)</b>	<b>mean</b>	<b>(SD)</b>	<b>mean</b>	<b>(SD)</b>		
PANSS subscales								
Positive	15.4	6.5	15.6	6.9	15.2	6.2	t= 0.06 (73)	0,951
Negative	14.4	4.7	13.8	4.8	15.1	4.5	t= -1.47(73)	0,015
General	26.8	7.5	26.5	7.9	27.1	7.2	t= -0.44(73)	0,663
Total	56.6	15.9	55.9	17.1	57.4	14.5	t= -0.42(73)	0,676
CGI	3.5	1	3.4	1	3.7	1	t= -0.96(68)	0.340
GAF	48.8	10.1	49.9	10.8	47.6	9.4	z= 1.170	0.242
CAN unmet needs	4.1	2.98	3.6	2.97	4.7	2.94	z= -1.705	0.088
EUROQUEL VAS	8.,4	20.7	84	21.2	84.8	20.4	z= -0.200	0.842
MARS	5.9	1.88	5.8	1.87	6.0	1.93	t= -0.36(71)	0.723

1. Baseline variables with missing data included: Marital status: n=6, ethnicity: n=6,HLOE: n=9, employment=9, PANSS: n=2, CGI: n=7, GAF score: n=14, CAN: n=6, EUROQUEL VAS: n=3, MARS: n=4

Half of the participants in the intervention group selected their mother to be their treatment partner, while the rest selected primarily immediate family members and partners. One participant selected a friend to be their treatment partner.

**Table 3-2 Treatment Partner Selections**

Selected Treatment Partner Type (n=37*)	n	%
Mother	21	56,8
Father	2	5,4
Sister	3	8,1
Brother	2	5,4
Aunt	1	2,7
Wife	2	5,4
Husband	1	2,7
Partner	2	5,4
Friend	1	2,7
Daughter	1	2,7
Son	1	2,7

\*The 37 participants who received the intervention

### 3.3.2 Outcomes

#### 3.3.2.1 Qualitative

##### ***MHSU Insight and attitudes***

MHSU insights and attitudes as elicited in the 3 month qualitative interviews are presented in Table 3-3 below. More participants in the intervention group had insight into their illness than did those in the TAU group. However, reported treatment adherence were similarly low in the two groups. More intervention participants reported finding the

structured psychoeducation session helpful than did TAU participants when asked about standard pre-discharge psychoeducation session.

Most of the treatment partners (52.9%) found the intervention session helpful in understanding the diagnosis and treatment regimen whereas caregivers found the standard pre-discharge psychoeducation contact inadequate and inconsistent in both these cases. More treatment partners knew and understood the diagnosis (23.5%) and syndromic features (47.1%) than did caregivers (5.9% and 0% respectively) who reported not having a good grasp of these. Caregivers and treatment partners showed similar low patterns of recall for information regarding specific medication and clinic follow up information. Participants and treatment partners in the intervention group felt that a psychoeducation follow up would be of even greater value in the long-term to reinforce knowledge and understanding. More participants in the intervention group (52.9%) were able to identify their diagnosis compared with participants in the TAU group (35.3%). See Tables 3-3 to 3-5 below.

**Table 3-3 MHSU insights and attitudes (Of the 17 reviewed in each arm) at 3 months**

	Intervention (n=17)		TAU (n=17)	
	n	%	n	%
Knows diagnosis	9	52.9	5	35.3
Understands illness	6	35.3	4	23.5
Understands the cause of illness	5	29.4	4	23.5
Knows medication regimen	10	58.8	8	47.1
Adherent to medication	10	58.8	11	64.7



**Table 3-4 MHSU perspective of Psychoeducation session for Intervention and Standard pre-discharge psychoeducation for TAU**

	Intervention (n=17)		TAU (n=17)	
	n	%	n	%
Recalls session	8	47.1	3	17.6
Session helpful for understanding diagnosis	6	35.3	2	11.8
Session helpful for understanding treatment	6	35.3	0	0.0
Recalls information on post-discharge follow-up	3	17.6	8	47.1

**Table 3-5 Caregiver perspective of psychoeducation session for intervention and caregiver perspective of standard pre-discharge psychoeducation for TAU**

	Intervention (n=17)		TAU (n=17)	
	n	%	n	%
Recall diagnosis	4	23.5	1	5.9
Understood syndromic features	8	47.1	0	0.0
Recalls medication information	2	11.8	2	11.8
Recalls post-discharge follow-up information	5	29.4	4	23.5
Found session helpful	9	52.9	1	5.9

### ***Text message component***

Some participants (7 of the 17 reviewed) and treatment partners (7 of the 17 interviewed) in the intervention group reported that they had not received the text message reminders. In spite of having had cell phones at enrolment, some participants did not have their own cellphones in the period following discharge from hospital and relied solely on their treatment partners to notify them of reminders. Participant and treatment partner contact numbers sometimes changed without the study team being notified, which meant the text message prompts would not reach the recipient. Some participants reported losing handsets, either accidentally or through theft. Those who received the text all reported

finding this helpful. Their reports were corroborated by the participants in their care. The mental health nurses at the clinic who participated in the study repeatedly expressed difficulty interacting with the text message software. Some of the processes of interacting with the system, such as needing to manually refresh the forms containing patient lists proved burdensome and challenging. The mental health nurses at clinic struggled to interact with the software on their handsets, in spite of reinforcement training sessions. This meant that at times they 1) would not have the appropriate forms to capture scheduled participants; 2) would not be able to check participants in when they arrived; 3) would not be able to administer the medication adherence question contained in the review form of the software; and 4) would not be able to schedule a follow-up appointment on the system. Not all the clinics had a secure space to store research handsets, so at times these had to be taken home by the nurse. As a result, one of the mental health nurses was mugged on her way home and the handset was stolen from her. Two of the handsets went missing from the clinic and could not be traced. All of these factors impacted negatively on the utility of the text message prompt platform. In another instance a staff member who had been trained in interacting with the software was on an extended leave of absence, without a replacement, which resulted in us not being able to get reliable data from that facility.

#### ***Medication and clinic visit adherence***

Participants in both groups reported similar experiences at the clinic. The clinic was overwhelmingly easy to access and navigate. Psychiatric clinic staff were reported to be supportive and helpful, with medication generally noted to be available as required at visits. Most of the participants found the period spent waiting to be seen by staff to be acceptable, while a small number experienced excessively long waiting periods. Treatment partners and caregivers reported similar patterns of participant medication adherence behaviour. Most participants were noted to be adherent to their medication while a smaller majority were

adherent to the clinic review appointments. Treatment partners were twice as likely to find the clinic helpful in supporting participant adherence. The experiences of being a treatment partner and of caregiving were similar amongst the two groups, with half in each group reporting a positive experience and the other half experiencing it as challenging. Impressions of whether any component of the intervention was more helpful than another were mixed, with no component being reported particularly superior.

**Table 3-6 Treatment partner and caregiver perspective on MHSU adherence behaviour**

	Intervention (n=17)		TAU (n=17)	
	n	%	n	%
Medication adherent	10	58,8	10	58,8
Clinic visit adherent	9	52,9	8	47,1
Found clinic helpful	11	64,7	5	29,4

The intervention thus appeared to be acceptable from the perspective of treatment partners and participants. The psychoeducation and the treatment partner components were feasible while there were significant challenges with the text message platform.

### ***Perceptions of caregiving***

Themes that emerged from the data included motivations for assuming the caregiver or treatment partner role, the participants' perceptions of factors impacting on caregiving, and perceptions of caregiving within the intervention.

Treatment partners from the intervention group and caregivers from the treatment as usual group felt responsible for the MHSU in their care, and were concerned about adherence. There were concerns around dangerous behaviour from MHSU when substance

use and non-adherence were involved. Relationships with other community members were put at risk as a result.

*“Even though I knew that I wouldn’t be able to do all the things that a partner should do, I just said yes I would be her partner because I knew there was no-one else “ (Treatment partner 1)*

*“actually, I was shocked when my mother told me (I was chosen to be treatment partner). So I didn’t actually know what it was about then the doctor explained so I thought okay, he’s (my brother) choosing me, he never chose my mommy or my daddy or anybody, he chose me, so I must take the responsibility now, try and help him” (Treatment partner 2)*

*“he’s interfering with the people in the street and he’s sometimes swearing in the ... there’s always a conflict on and I’m the mother, I must always be in the middle, ... It’s sometimes very hard for me to cope with F because F sometimes get very out of hand, ..., ..., I don’t know did you see his reactions, he’s not himself because he’s not on treatment. But when he use his tablets then he’s calm, then I can go anywhere with him.” (Caregiver 1)*

One treatment partner saw her role as helping the MHSU grow without being limited by his disability. The importance of patience was expressed, when caring for a family member with severe mental illness.

*“I can move forward, my disability mustn’t (hold) me back in life, it must give me that push in life and say, I can do more, I can do more. This is what I’m saying, if there’s anybody needing help, get a partner and that partner must be positive “ (Treatment partner 4)*

*“you must have patience and show him you love him and everything and as a family you sit together and we talk to each other and make each other happy you*

*see and maybe that's what he was looking for all the time and I didn't realize it "*  
*(Treatment partner 5)*

Socioeconomic factors such as food insecurity and substance abuse impacted negatively on adherence. Aggression made it difficult to provide support for MHSU, especially in an environment overrun by gangsterism and crime.

*I feel that it is quite strong, the medication's quite strong and I didn't, at home there's not enough food to eat to balance out, to support the strength of the tablets with the food and, but I took my injection regularly, it's also the complex injection, a substantial amount of food to support the strength of the tablets, you understand there's not enough finances at home ... (MHSU 3)*

*this morning there wasn't anything to eat, you see, so I couldn't give him his pill, but I gave a little bit, just a bit, because he couldn't have a whole one because we didn't eat ... (Treatment partner 6)*

*it's his friends [who are involved in gangsterism] that give (TIK – Methamphetamine) A's using this TIK now, he was in a terrible state he was like getting aggressive with the people and banging this, knocking the, kicking this man's car and the man came to complain, A started to grab me one very early morning ... he pushed me and he pressed me in the wardrobe, I didn't scream, I didn't panic. (Treatment partner 3)*

*I don't ever go into that area ... there's too much in the newspapers and a family member of ours was recently shot there, so I don't ever go into that area. We (the mother and I) talk about P, I always ask how she is now and then her mom will tell me ... she was at the place she gets her pills ... (Treatment partner 1)*

*(he) went for this TIK (methamphetamine), now he's uncontrollable, he stole to sell for drugs. I said did you take (your medication) already, as soon as you've finished your breakfast you must take it, he said no, no, I'm going to take it and I, as time*

*went then he doesn't take his medication. He went for TIK now, now he's so, so, in a terrible, terrible state. (Treatment partner 3)*

Some treatment partners had changed since the start of the intervention, with one of the participating MHSU being supported by his landlady instead of his mother as arranged. Another had selected his brother as his treatment partner but was now being supported by his mother. This was due to family responsibilities and employment opportunities.

*"I stay there, I pay my board, I pay my rent, I get my food everything ...*

*Interviewer: and she reminds you to take your medication?*

*Respondent: yes" (MHSU 4)*

*I'm not actually there anymore so my mother's looking after him during the day, so my mother told me a few days ago he didn't want to take it (medication), he never went to fetch it at the clinic ... (Treatment partner 2)*

Poor mental health knowledge was identified as a factor that made it difficult to provide support for MHSU. For one caregiver in the TAU group, knowledge about schizophrenia had remained poor in spite of having attended multiple psychoeducation sessions at Valkenberg hospital with her brother, a MHSU. She suffered from her own depressive illness while supporting her brother. She felt this was a barrier to her ability to provide care for her brother.

*I think I still need to know more information about what is the meaning of the words and the meaning of schizophrenic you know, but another thing you know, my mother, she also had a nervous breakdown when we were very young and I think it's something hereditary or something I don't know, because I'm also suffering from a major depression disorder ... (Caregiver 3)*

MHSU in the TAU group expressed similar sentiments of not having a good grasp of their own mental illness.

*Interviewer: 'do you know what your diagnosis is?'*

*Respondent: 'they didn't tell me'.*

*Interviewer: 'so you're not sure what your diagnosis is?'*

*Respondent: 'they just said it was drugs related'. (MHSU 5)*

*Interviewer: 'what do you think made you sick?'*

*Respondent: 'the fact that I'm not working or doing anything ...'*

*Interviewer: 'and anything else?'*

*Respondent: 'nothing'. (MHSU 6)*

Some caregivers and treatment partners had to deal with the added burden of their own mental or chronic medical illness, or that of other family members. Some caregivers reported that as a result they had adopted family adherence approaches, while others provided a more individualized support approach.

*my mother gives him the tablets and they (the other family members) watch him (take their medication) ... (Treatment partner 2)*

*because every morning I take my medication then he takes his, he had to take his medication, coz my son also takes medication, that is bed ridden and I myself take my medication ... (Treatment partner 7)*

*I'd say it's been a good help for me, it makes me realise I also have to take my tablets (for arthritis and hypertension) ... (Treatment partner 5)*

One treatment partner reported that psychoeducation had helped improve her knowledge but that it would be helpful if it could be reinforced. She found the role of treatment partner to be a useful one.

*I have more information about this sicknesses and I think it would be more helpful for me to know this is how I am supposed to treat him. I shouldn't treat him otherwise as I'm treating him, but it would have been better for me to know that*

*this is T's situation and is there something that I can do to change it or whatever ...  
(Treatment partner 8)*

*well I want to move forward, there's more things in life that I can achieve. You see  
and that makes it helpful for them, if you, the partner is positive, it mustn't be  
negative about things going around, whether he's sick or whatever, but you must  
be positive of helping that person and say to that person, look here man, you don't  
have to stay here, there's more things in life that you can achieve ... (Treatment  
partner 8)*

### **3.3.2.2 Efficacy Outcomes**

Efficacy outcome data are represented in Tables 3-7 and 3-8 below. Data for clinic visits and readmission was complete. The PANSS and other efficacy outcomes had incomplete outcome data as only 34 participants out of the randomized 77 attended the study visit at 3 months. Participants in the TAU group were more likely to not attend their first clinic visit than those who had received the intervention, but this was not a statistically significant difference (RR 0.79 p value 0.42, CI 0.44-1.39). TAU participants were marginally more likely to be readmitted in the 9 months following discharge (RR 0.86, p value 0.71, CI 0.39-1.87). At 3 month review, TAU participants showed a marginally increased likelihood of worsening scores on the total and positive-subscale scores of the PANSS, while GAF scores showed better improvement amongst participants in the intervention. CGI scores suggested a clinical impression of symptom improvement for the group that received the intervention while the GAF scores of both groups suggested general improvement in functioning. There was a trend towards an increase in unmet needs in the TAU group vs a decline in unmet needs in the intervention group, while met needs were seen to increase in both groups.



**Table 3-7 Efficacy outcomes**

Intention-to-treat analysis (ITT): Non -adherence to first clinic visit, re-admission over 9 months								
Outcome	Risk Ratio (ITT)							
			Unadjusted	Adjusted <sup>1</sup>	p-value	95% CI		
	n	%	(n=77)	(n=77)				
Non-adherence to first clinic appointment								
Intervention (n=42)	14	33.3	0.72	0.79	0.419	0.44 – 1.39		
Treatment as usual (n=35)	16	45.7	-	-	-	-		
	Risk Ratio (ITT)							
			Unadjusted	Adjusted <sup>2</sup>	p-value	95% CI		
	n	%	(n=77)	(n=77)				
Any re-admission over 9 months								
Intervention (n=42)	5	11.9	0.83	0.86	0.713	0.39 – 1.87		
Treatment as usual (n=35)	5	14.3	-	-	-	-		
Complete case and intention to treat analysis (ITT) of other efficacy outcomes at 3 months.								
Outcome	Complete case analysis <sup>3</sup>				ITT			
	(Intervention vs. TAU)				(Intervention vs. TAU)			
	Mean difference <sup>4</sup>		p-value	95% CI	Mean difference <sup>5</sup> (n=77)		p-value	95% CI
Unadjusted	Adjusted	Unadjusted			Adjusted			
PANSS score								
Total score	-9.4	-14.7	0.052	-29.71 – 0.16	-13.4	-13.1	0.062	-27.00 – 0.73
Positive subscale	-3.8	-6.4	0.011	-11.20 - -1.60	-5.6	-5.4	0.060	-11.16 – 0.25
Negative subscale	-2.6	-4.4	0.059	-8.99 – 0.18	-3.5	-3.5	0.078	-7.52 – 0.43
General subscale	-2.8	-3.9	0.350	-12.61 – 4.68	-4.4	-4.2	0.248	-11.67 – 3.19
MARS	-0.21	-0.75	0.425	-2.68 – 1.17	0.36	0.49	0.603	-1.44 – 2.43
CGI	-0.8	-0.58	0.346	-1.84 – 0.67	-	-	-	-
GAF	7.5	4.1	0.440	-6.90 – 15.17	-	-	-	-
CAN					-	-	-	-
Total needs	-	-	-	-	-	-	-	-
Unmet needs	-3.2	-3.6	0.029	-6.74 - -0.49	-	-	-	-
Met needs	-	-	-	-	-	-	-	-
EUROQUEL-VAS	16.1	15.2	0.124	-4.59 – 34.99	-	-	-	-

<sup>1</sup>Log-Poisson regression model with robust variance estimation, ITT; adjusted for age, sex, substance use disorder, baseline scores of PANSS total score, GAF score, MARS, EUROQUEL VAS scale, CANSAS unmet needs score. <sup>2</sup>Log-Poisson regression model with robust variance estimation, ITT; sex dropped from model, adjusted for adjusted for age, substance use disorder, baseline scores of PANSS total score, GAF score, MARS, EUROQUEL VAS scale, CANSAS unmet needs score. Baseline data were imputed. <sup>3</sup> Multiple linear regression models adjusted for age, sex, substance use disorders, baseline scores of PANSS total score, GAF, EUROQUEL, MARS, CANSAS unmet needs. Models with violation of linear regression assumptions omitted. <sup>4</sup>Sample size varied due to list-wise deletion. <sup>5</sup>Only models for which missing data <55% are reported

### 3.4 Discussion

The main findings of this study were that 1) The treatment-partner focus and the psychoeducation component were acceptable and feasible; 2) The text message component was acceptable but it was not feasible in its current form; and 3) Efficacy outcomes favoured the intervention but did not reach statistical significance.

The acceptability and feasibility of this treatment-partner intervention is consistent with the findings of my systematic review in Chapter 2, as well as with a great deal of prior literature (Inge Petersen, Lund, & Stein, 2011a; van Ginneken et al., 2013a). The psychoeducation session was particularly well received. My approach was in line with previous caregiver focused interventions for MHSU, which have targeted mental health literacy and considered the impact of access to support networks on the experience of caregiving. Family psychoeducation interventions have been shown to reduce relapse in people living with SMI, while helping to meet the needs of caregivers engaged in providing support for MHSU (Miklowitz, 2004; Pickett-Schenk et al., 2006). While it has been more difficult to change coping styles, and reduce caregiver distress and psychological burden, short term interventions have been shown to have a moderate impact on caregivers' mental health knowledge and on improving attitudes towards MHSU and mental illness (Rahmani, Ranjbar, Ebrahimi, & Hosseinzadeh, 2015; Szmukler, 1996).

From the 3 month interviews the findings were that 1) treatment partners and caregivers, who are often family members, feel obligated to care for MHSU, but may also derive fulfilment from the caregiving relationship; 2) Caregivers' and treatment partners' understanding of mental illness is limited; 3) Treatment partners find it difficult to negotiate harsh environments where there are several factors, including substance abuse and violence, which increased risk for poor adherence and readmission to hospital, and that 4) treatment partners' circumstances may change e.g. having to move out of the home where

their MHSU resides for employment opportunities, impacting on their direct availability to provide support.

Treatment partners and caregivers feel obligated to care for MHSU, who can be dependent on their treatment partners/caregivers to remind them to take their medication. In formative research I found that family members were natural caregivers as they lived in the same residence as the MHSU in their care (Mall et al., 2013). This also emerged in a study investigating the feasibility of family therapy for schizophrenia through a qualitative design (Asmal, Mall, Emsley, Chiliza, & Swartz, 2014). Family members in this study expressed a desire to protect the MHSU in their care from stigma and abuse, a theme echoed in another study exploring caregivers' views on housing and living with mental illness (Browne & Hemsley, 2010). Improved holistic interventions for MHSU which include protective, supportive structures for community and caregivers, can go a long way towards easing the burden on caregivers (Awad & Voruganti, 2008). A positive caregiving experience served to reinforce the caregiver role, while supportive community structures such as the church, were important. These findings are consistent with previous work showing that supportive family relationships added to caregiver satisfaction, as did structural health system support (Kartalova-O'Doherty & Tedstone Doherty, 2009).

Poor mental health knowledge emerged as a concern for participants. While the impact of psychoeducation was not objectively measured, qualitative feedback from participants was mixed. Some reported experiencing the psychoeducation component positively, and others indicated dissatisfaction. The impact of psychoeducation has previously been found to be inconsistent (Sin, Jordan, Barley, Henderson, & Ij, 2013). A family psychoeducational intervention was noted to reduce burden in caregivers of MHSUs with schizophrenia (Gutierrez-Maldonado & Caqueo-Uriazar, 2007). The impact of psychoeducation on psychological distress has been found to be delayed, and not

immediately appreciable post-intervention (Yesufu-Udechuku et al., 2015). This suggests that much still needs to be done to ascertain the most effective approach to deliver appropriate and useful psychoeducation for the caregivers of MHSU.

Caregivers and treatment partners in this study had to contend with a high burden of care, as well as harsh environments ridden with violence, substance abuse and food insecurity. Caregivers may view MHSU with a history of violence negatively, especially where violence has been directed towards the caregiver (Onwumere et al., 2014). The result is low self-esteem among caregivers. Lay health workers working with MHSUs with extreme social difficulties or alcohol related problems had particular difficulty where interventions seemed unable to address their specific needs, while these factors have been correlated with increased emotional distress and burden amongst caregivers (Pereira et al., 2011; Vaddadi, Gilleard, & Fryer, 2002). The increased burden placed by substance use on family relations has the impact of reducing the amount of support they give, while there is a suggestion that in fact direct family support may help reduce or eliminate substance use in people with mental illness (Clark & Drake, 1994; Clark, 2001).

Socioeconomic factors have a clear impact on the caregiving relationship. Caregivers sometimes need to relocate to areas where employment might be more easily obtained. This, in addition to factors around their own mental illness, and burden of other responsibilities, directly impacts on their availability to provide support to the MHSUs (Aengibise, Doku, Asante, & Owusu-Agyei, 2015). The issue of food insecurity also emerged from the MHSUs who found it challenging to adhere to their medication when they experienced chronic hunger. Kartalova-O'Doherty and Tedstone Doherty found that carers with a higher socioeconomic status experienced more satisfaction in their caregiving role (Kartalova-O'Doherty & Tedstone Doherty, 2009).

For MHSU, brief psychoeducation (10 sessions or less) has been shown to reduce relapse in the medium term and promote medication adherence in the short term (Zhao, Sampson, Xia, & Jayaram, 2015). Studies have shown findings of improved clinical outcomes including reduced relapse and readmission with improvement in treatment adherence (Xia, Merinder, & Belgamwar, 2011). Many of the participants reported experiences of inadequate and inconsistent current psychoeducation approaches within the standard MHSU discharge process, potentially pointing to inadequate routine discharge planning. Good, comprehensive discharge planning, which has been associated with improved post discharge adherence for MHSU, may be affected by the quality of the therapeutic alliance, which in turn is often impacted by the clinical experience of the psychiatric practitioner (Fenton, Blyler, & Heinssen, 1997; Foli-Andersen, 2014; Han et al., 2015; Steffen, Kösters, Becker, & Puschner, 2009).

Text messaging has been suggested as a promising and acceptable tool to aid medication and clinic adherence support in mental illness (Bogart et al., 2014; Watson, Simpson, & Hughes, 2016). The evidence base on the effects of such prompts in improving adherence however remains inconclusive (Kauppi et al., 2014). The formative work found support for text message prompts (Mall et al., 2013). There were however, several challenges during the trial which impacted the utility of this m-health component. These included intervention participant factors such as not having a mobile phone, changing mobile numbers and loss of mobile handsets through theft or misplacement. Fieldworker factors included software challenges, a staffing change, and loss of handsets through theft. It therefore became clear that socioeconomic factors and the complexity of the software were significant limiting factors on the feasibility of text message prompts in our setting.

### **3.5 Limitations**

While the preliminary efficacy outcomes favoured the intervention, an important limitation is the small sample size, which was insufficient for statistical significance. Importantly however, the primary focus of this study was on acceptability and feasibility, and the work done here allows a power analysis for future efficacy research using larger samples (my power analysis using the obtained data indicated that a sample size of 520 would be required to yield statistically significant results for an efficacy study). Second, the mental health nurses experienced challenges interacting with the text message platform. This may have compromised data input and appointment checking and rescheduling. An additional limitation is that MHSU declining participation in the study were not asked to provide reasons for declining. I was therefore unable to provide insight into reasons for opting out of the study.

### **3.6 Conclusion**

Psychoeducation in its current form is limited, and potentially represents a shortcoming of current routine discharge planning standards. MHSU and their caregivers, who are natural adherence support resources for MHSU, would benefit from more comprehensive and reinforced psychoeducation. Recruiting caregivers into a negotiated treatment-partner role, supported by psychoeducation, is an acceptable and feasible approach in a LMIC setting. While mental health literacy is an important component of support for caregivers, it is best for psychoeducation interventions to be tailored to the needs of the specific population targeted, and take into account the need for ongoing reinforcement. M-health approaches could potentially be helpful in supporting adherence in chronic illness, but text message prompts may be problematic in some LMIC settings, such as our own, at present. Additional components of such an intervention should be tailored to the local context. The assessment of efficacy for such an intervention requires appropriately powered studies.

## **Chapter 4 Community health worker intervention**

The intervention presented in Chapter 3 involved level 4 task shifting, focusing on the shifting of adherence support roles to individuals in the MHSU's existing support structure. The findings suggested that more work needs to be done to fine-tune this approach to adherence support. This chapter reports on a mental health training intervention for community health workers (level 3 task shifting) who provide such support and care at community level. A background to the intervention is provided, followed by a description of the methods employed, from development of the intervention, to the outcome evaluation and findings.

### **4.1 Background**

The pilot RCT intervention described in chapter 3 adopted an approach that focused on respecting and protecting MHSU autonomy, both in intervention design and in the design of the treatment partner relationship, in line with the concept of shared decision-making in mental health (Slade, 2017). Other evidence-based adherence-supporting interventions for mental health such as Assertive Community Treatment (ACT) and those delivered by CHWs offer a more active approach to adherence support (Allen, Sugarman, & Wennerstrom, 2017; Botha, Koen, Galal, Jordaan, & Niehaus, 2014). In the investigation described in this chapter, the focus is on CHWs. It has been mentioned in Chapter 1 that the evidence for interventions delivered by CHWs, which while still requiring further evidence for mental health, has yielded some positive outcomes in other areas such as HIV, TB malaria and maternal and child health (Lassi & Bhutta, 2015; Lewin et al., 2010; Okwundu, Nagpal, Musekiwa, & Sinclair, 2013; van Ginneken et al., 2013a).

CHWs in Cape Town provide home based preventive, supportive and rehabilitative care under the supervision of various non-profit organizations (Western Cape Government Health, 2014)(Western Cape Government Health, 2014). They provide general medical

support with a focus on reducing risk factors that contribute significantly to the burden of disease, which includes support for MHSU. CHW's in the Western Cape receive training in the provision of chronic care, including that for hypertension, diabetes, TB and HIV. Although the NPO contracts include support to MHCU, there is currently no standard mental health-training or existing training programme for CHWs in this region.

Little is known about the specific characteristics of current training interventions for CHW (Viswanathan et al., 2009). It is unclear whether structured CHW training focussed on mental health results in improved knowledge, confidence and a change in attitudes towards mental illness. A locally appropriate structured CHW mental health training programme was therefore developed, in close collaboration with the Western Cape Department of Health (Innvaer, Vist, Trommald, & Oxman, 2002). An evaluation followed, of the programme's success in improving the knowledge, confidence and attitudes of CHWs. Training evaluation was conducted from the perspective of the CHWs, in order to determine the acceptability and appropriateness of the programme, which factors which have been linked to the success of programmes aimed at CHWs (Glenton et al., 2013).

The theory of change is an approach to the development of complex interventions, which accounts for the manner in which early and intermediate interventions are designed and planned for the achievement of a longer-term outcome or goal (Anderson, 2014; Coryn, Noakes, Westine, & Schröter, 2011). In keeping with this approach, as used widely by groups such as PRIME, the long-term change of interest is the improved quality of home and community-based mental health services (Breuer et al., 2016). Through interactions with stakeholders in the department of health, it was established that the concern of the WCDoH was the absence of mental health training for mental health workers, which it was felt was a limiting factor to the quality of care available for MHSU from home-based care services. Through these interactions it was possible to identify the specific training needs and



incorporate them into the design of the training programme, as described in the text below. The aim was first to first upskill the CHW's tasked with providing that home-based care, with the assumption that the resulting improved knowledge, skill, confidence and attitudes in the short and medium term would result in an improvement of the quality of care delivered, and bring us closer to achieving the long-term change.

## **4.2 Methods**

### **4.2.1 Study Design**

A quasi-experimental (before-after) cohort intervention study design was employed to evaluate the training programme. This design is ideal for the comparing naturalistic units such as CHW groups (Handley, Schillinger, & Shiboski, 2011). Data were collected at baseline, at the end of each training session, and at the end of the training programme. All data were collected anonymously through the use of a unique identifier assigned by NPO supervisors, on questionnaires to allow for matching of pre- and post-training data. Any document containing the information linking trainees to their unique identifier was kept confidentially in a password protected spreadsheet. Any electronic records are password-protected.

### **4.2.2 Ethics and informed consent**

This study was approved by the Human Research Ethics Committee of the Faculty of Health Sciences at the University of Cape Town (HREC 913/2015). Written informed consent was obtained from all participating CHWs, who all received a copy of the study information and their signed consent. No information was withheld from participants. Participants were not reimbursed, however refreshments were provided during the conduct of the course. All data were collected anonymously through the use of a unique identifier, on

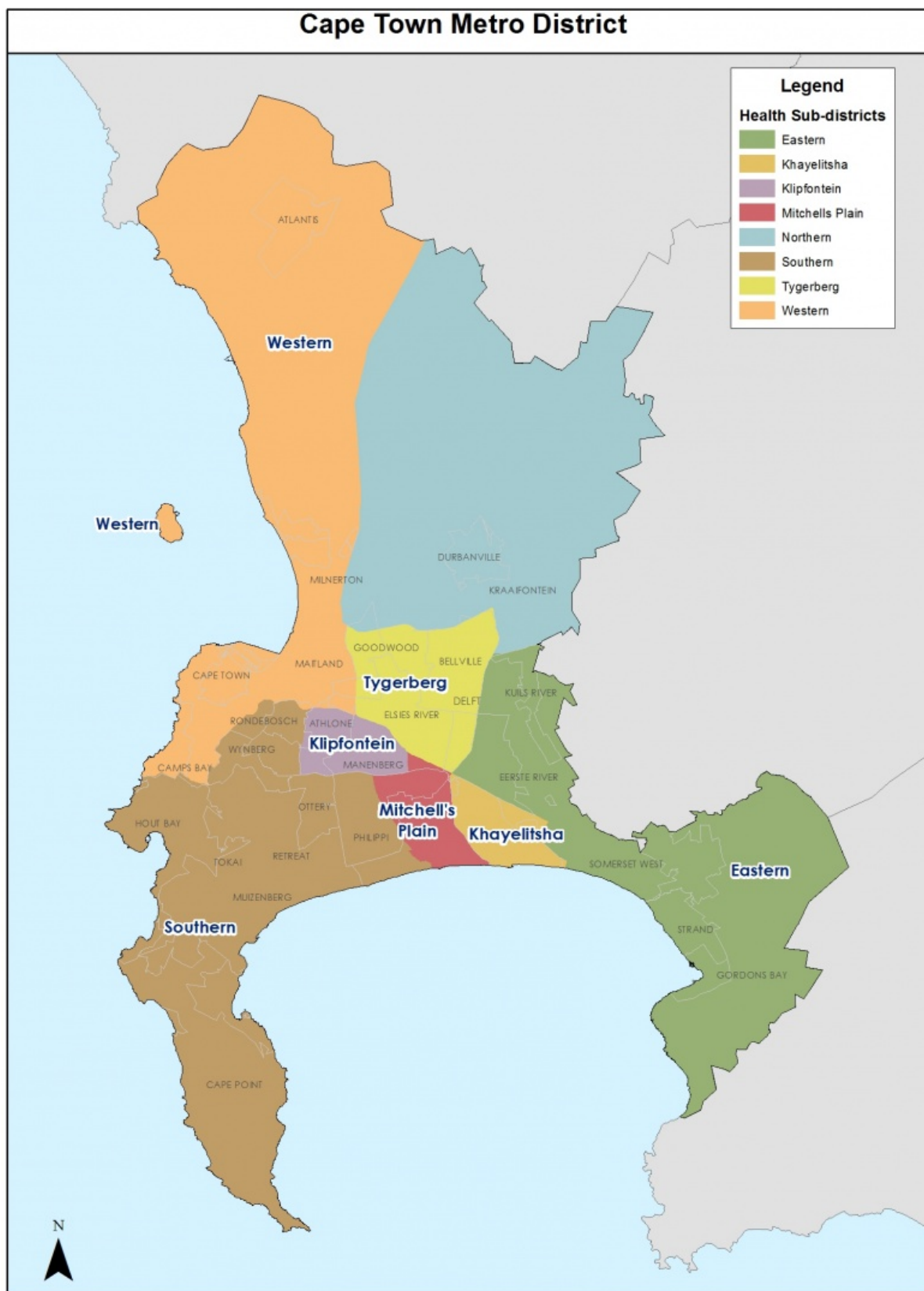
questionnaires to allow for matching of pre- and post-training data. Any document containing the information linking trainees to their unique identifier was kept confidentially in a password protected spreadsheet. The study was registered with the Pan African Clinical Trials Registry (PACTR201610001834198).

#### **4.2.3 Study sites and participants**

There are four psychiatric hospitals in the Western Cape (Western Cape Government, 2017b). Alexandra Hospital in Maitland, Lentegeur in Mitchell's Plain, Stikland Hospital located in Bellville, and Valkenberg Hospital located in Observatory. New Beginnings is a sub-acute facility which falls under Stikland Hospital's supervision. William Slater provides a mental health step-down facility under Valkenberg Hospital. These hospitals provide tertiary in- and out-patient psychiatric services, within a network of health facilities that include clinics, Regional and District Hospitals, and Community Health Centres, ensuring they are embedded within the general care settings and integrated into primary care in line with the South African Mental Health Care Act 17 of 2002 (South African Government, 2002). This allows for mental health care to be delivered at less specialized facilities where possible, with reserving specialized care for those who need it. The Western Cape is divided into health districts, which plan, execute and oversee delivery of this integrated care (See Figure 3-1). The Health districts are further divided into substructures, which in addition to being responsible for primary health care, oversee a range of community based health services. In the Cape Town Metro, the four sub-structures each contain two sub-districts. CHW's form an important part of these community-based services and are arranged in groups ranging in size from 20 to 40, supervised by Non-Governmental Organizations (NGOs). Four health sub-districts were identified within the Cape Town region, in consultation with the WCDoH for the piloting of the training manual.

The first draft of the training programme was used to train 20 CHW's supervised by The Caring Network Khayelitsha in the Khayelitsha sub-district and 22 CHWs supervised by Arisen Women Foundation in the Klipfontein sub-district. The final draft of the training programme was piloted by training 27 CHW's supervised by Masincedane in Strand and 36 CHWs supervised by Opportunity To Serve Ministries (OTSM) in the Mitchell's Plain sub-district. There were no exclusion criteria as this type of training falls within the scope and job description of these CHWs. The CHW supervisors, to whom the CHWs report directly, were part of the training cohort.

Figure 4-1 Cape Town Metro District and Health Sub-districts



Source: <https://www.westerncape.gov.za/image/2012/10/ct-sub-districts.jpg>

#### 4.2.4 The training programme

Development of the training programme began with a review of the processes and experiences of mental health training that had been conducted with a group of CHWs in the Tygerberg sub-district. This training had been developed by New Beginnings to train CHWs within their sub-district. Details of this training were provided to us by the Western Cape Department of Health (WCDoH), and contained feedback from the CHWs who had received this training and from the trainer who had delivered the training, and who continued to work with me in this project.

**Figure 4-2 Western Cape Department of Health, represented by Mrs. Marinda Roelofse**



Mrs Roelofse is Deputy Director of Mental and Substance Use, NCDs, Rehab, Audiology & Speech, and Older Persons

The training programme is in line with South African National framework for CHWs as developed by the Health and Welfare Sector Education and Training Authority (HWSETA, 2015). Development was guided by the principles outlined in the “UNESCO Training Guide and Training Techniques” and the “Best Practice Guidelines for Implementing and Evaluating CHW Programs in Health Care Settings” documents (Gutierrez & Campbell, 2014; UNESCO Bangkok, 2004).

The themes covered in the New Beginnings training were developed, and inspiration drawn from the training manual developed by Gibson et al. (Armstrong et al., 2011; Gibson et al., 2010). The education and intervention guidelines were drawn from the WHO Mental Health Gap Action Programme (mhGAP) Intervention guide (World Health Organization, 2016). Information pertaining to admission pathways and role players is based on the South African Mental Health Care Act No. 17 of 2002 (South African Government, 2002). The programme takes into consideration locally accepted theories of disease causation and prevailing beliefs as these impact not only on stigma and health seeking behaviour, but also on clinician symptom appraisal and intervention decision-making (Warner, 1977). A draft of the training programme was presented to the clinical teams of the Khayelitsha and Mitchell's Plain health sub-districts for their inputs, which included specific concerns around language and target proficiency for the CHWs. Adjustments were made accordingly and updated documents shared with all stakeholders at each point.

The first draft of the training program was used to train two groups of CHW's described above in June 2016. The purpose of this was to evaluate the appropriateness of the content and language and to make final adjustments based on the feedback of the CHWs receiving this initial training. This version of the training programme was well received by the CHWs. The participants in general expressed appreciation and gratitude for the training programme, and were satisfied with the content and the conduct of the training, expressing that they would have appreciated the opportunity to have more such training. CHW's perceived the content of the programme as interesting and informative, covering areas of types of mental illness and how to treat them. The content was viewed as relevant and appropriate. CHW's expressed that they had encountered many of the items discussed in the training in their work but had never received training about it. They now felt more equipped to deliver mental health support. CHWs felt that the training had been delivered clearly and effectively. Feedback regarding course duration was that it should be longer so



the topics can be covered in more depth. One CHW suggested that an annual training would be helpful in retaining the information. The content of the manuscript was modified during this initial training as the course conduct was being observed and as feedback was being received both in-person and in writing from the CHWs.

**Figure 4-3 The community health workers of Arisen Women Foundation in Mitchell's Plain**



**Figure 4-4 The Community health workers of Caring Network Khayelitsha in Khayelitsha**



Following this process, the final programme was prepared and piloted in February 2017. The final training programme, consisting of eight 3-hour sessions was prepared and piloted in February 2017 (G Sibeko, 2016). The outline of the programme is presented in Figure 5-1 below. Each session is divided into activities covering specific components. Step-by-step instructions are provided to assist the facilitator in conducting each activity to ensure that the training objectives of the session are met. The focus of facilitation is on encouraging trainee participation through reflection and discussion. There is significant provision for revision of previously covered content as the programme continues.

**Figure 4-5 The community health workers of Masincedane Community Service in Strand**



**Figure 4-6 The community health workers of Opportunity to Serve Ministries in Mitchell's Plain**





**Figure 4-7 Outline of training programme**

Session	Topic	Elements
1	Introduction and Culture	Ice breaker session, pre-training evaluation forms, and discussion of culture.
2	Culture and Mental Illness	Introduction of mental illness and it's overlap with local cultural constructs.
3	Mood and Anxiety Disorder	Discussion of the features of these components.
4	Psychotic Disorders, Older People, Intellectual Disabilities, Suicide and Aggression	Discussion of the features of these components and an approach to suicide and aggression.
5	Substance Use Disorders and Management of Mental Illness	Discussion of substance use, abuse and dependence and the management of previously introduced mental illnesses.
6	The Role of the CHW	Discussion of the role of the CHW, a review of mental disorders previously discussed, and a discussion of adherence and general support skills
7	The Mental Health Care Act and Admission Pathway	Discussion of the mental health act, evaluation and admission pathways and processes.
8	CHW Experiences, Case Vignettes, Evaluation Forms and Closure	The CHWs reflect on their training and experience in the field, and complete the post training evaluation documents.

#### **4.2.5 Delivery of the training**

The training programme was delivered by a trilingual (English, Xhosa and Afrikaans) social worker (LM) with extensive experience in training and in multidisciplinary mental health service delivery. The training was hosted at facilities provided by the NPO's and was presented with the aid of a PowerPoint presentation. Reflection and discussion was encouraged during the conduct of the training.

**Figure 4-8 Training session underway with the Masincedane community health workers**



#### **4.2.6 Evaluation and measures**

*Knowledge:* Mental health knowledge was measured through the use of case vignettes and by using the Mental Health Knowledge Schedule (MAKS) (Evans-Lacko et al., 2010). Case vignettes questions sought to assess diagnostic areas covered in the training, and were designed to elicit the CHW's impression of likely diagnosis, appropriate intervention and the role of the CHW in management. The focus was not on the specific language used to identify diagnosis but on whether CHWs were able or not to identify the correct diagnostic group. This chapter reports only on the diagnostic accuracy. The MAKS, which is a widely used measure of mental health knowledge (Wei, McGrath, Hayden, & Kutcher, 2015), consists of 12 statements scored on a Likert where a score of 1 corresponds to a scenario where the respondent strongly disagrees with a correct statement and a score of 5 corresponds to a scenario where a respondent strongly agrees with a correct statement (Evans-Lacko et al., 2010). The last 6 statements are intended to measure levels of

recognition of various mental health conditions. Item scores were added up to arrive at a total score.

*Confidence:* Confidence in executing mental health care support was measured using the Mental Health Nursing Clinical Confidence Scale (MHNCCS) (Bell, Horsfall, & Goodin, 1998). The MHNCCS is a self-completed instrument composed of 20 items scored on a Likert scale, where a score of 1 indicates “not at all confident” and a score of 4 indicates complete confidence.

*Attitudes:* Changes in personal attitude towards mental illness were measured using the widely used Community Attitudes Towards The Mentally Ill Scale (CAMI) (Taylor & Dear, 1981; Wei et al., 2015). There are 4 clusters for the CAMI: authoritarianism, benevolence, social restrictiveness and Community Mental Health Ideology (CMHI) which indicates tolerance to rehabilitation in the community, divided into an equal number of positively and negatively worded items.

*Acceptability and feasibility:* Acceptability was evaluated through the use of daily evaluation questionnaires and a training evaluation form. Feasibility was established through the appraisal of the quality of stakeholder participation and enabling activities within the local primary care system.

*Evaluation procedures:* The questionnaires were conducted at the beginning of training and again at the end of the training. Case vignettes and the Mental Health Knowledge Questionnaire were repeated three months after the end of the training to determine knowledge retention. At all assessment points, case vignettes were conducted first and then collected before the rest of the questionnaires were handed out and completed in order to ensure that case vignette responses were not modified by the content in the questionnaires. Daily evaluation forms were completed by the CHWs at the end of each training session where participants were asked what they enjoyed most about the

session, what they had learnt during the session that they felt would be most useful for their work, whether there was anything they had failed to understand during the session, what they had learnt that was most important to them. A training evaluation was conducted on the last day of training, enquiring about the content of the training, the tools and processes used during training, the performance of the trainer, the training setting, the usefulness of the training, as well as an overall impression of the training.

**Figure 4-9 Questionnaire completion by community health workers at Opportunity to Serve Ministries**



**Figure 4-10 Outcomes and measures**

Outcome	Measure	Collection point
Knowledge and skill	Clinical case vignettes	Administered before the start of training, and at the completion of training
	Mental Health Knowledge Questionnaire	
Confidence	Mental Health Clinical Confidence Scale	
Attitudes	Community Attitudes Towards The Mentally Ill Scale	
Acceptability	Daily Evaluation Questionnaire	Completed at the end of each session
Feasibility	Training Evaluation	Completed at the end of the training

#### **4.2.7 Analysis**

The primary outcomes were 1) change in the CHW's mental health knowledge; 2) change in CHW confidence in supporting MHSU and 3) change in attitudes towards mental illness, amongst the CHWs receiving the training. T tests and regression models were used to test changes in questionnaire scores before and after completion of the training, adjusting for baseline scores. Data was entered and analysed using the R statistical computing platform (Version 3.4.1) (R Core Team, 2017).

Qualitative data collected at the end of each training session was managed and analysed using NVIVO 8, following which an inductive thematic analysis approach was adopted (Braun & Clarke, 2012). Data were collected at the end of every training session using daily evaluation questionnaires, and at the end of the training programme via a freeform entry field within the training evaluation questionnaire. Two investigators (GS and DJ) familiarized themselves with the data and generated codes. Once codes were reviewed and agreed upon, they were grouped into potential themes, which were then defined and named, and which are presented below.

### **4.3 Results**

#### **4.3.1 Participants**

The characteristics of the participants are presented in Table 4-1 below. Fifty-eight CHWs participated in the study (31 from Masincedane and 27 from OTSM). None of the participants reported having their own psychiatric illness or having someone in their home with a psychiatric illness. Their CHW work was in general their only employment and source of income. Forty (69.0%) of the 58 CHW's enrolled into the training attended all 8 sessions, while 15 (26.0%) attended 7 of the 8 sessions. Only 1 (1.7%) attended 6 sessions, while two

CHW's dropped out during the course of the training due to overlapping training commitments, attending 1 and 5 sessions respectively.

**Table 4-1 Participant characteristics**

	<b>Masinedane</b>	<b>OTSM</b>
	<b>(N = 31)</b>	<b>(N = 27)</b>
<b>Characteristic</b>	<b>(Mean, SD)</b>	<b>(Mean, SD)</b>
Age	32.3 (7.72)	41.48 (12.57)
Service	3.86 (3.94)	2.79 (2.44)
Highest Level of education in grades	11 (0.96)	10.81 (1.4)
Children	1.96 (1.16)	1.9 (1.16)
Dependents <sup>a</sup>	4.56 (3.71)	3.06 (2.34)
	<b>%</b>	<b>%</b>
Stable partnership <sup>b</sup>	40.74%	58.06%
Has own medical condition	22.22%	41.94%

<sup>a</sup> Dependents refers to total of dependents of different age categories (<5, 5-18,18+).

<sup>b</sup> Stable partnership refers to any marital, customary or committed relationship

### 4.3.2 Quantitative

#### 4.3.2.1 Knowledge

**Case Vignettes:** Of 46 individuals with complete pre-and post-intervention data, a total of 29 (63.04%) improved in accuracy of diagnosis for the case vignettes, 9 (19.57%) had no change in knowledge, and knowledge got worse in 8 (17.39%). Amongst those who improved, there was approximately a 100% increase in diagnostic accuracy (from mean accurate diagnoses (SD) of 2.03 (1.27) before the intervention, to 4 (0.96) after the intervention). A logistic regression modeling approach was employed, in which the outcome,

likelihood of improving in knowledge from pre-to post intervention was regressed on pre-intervention knowledge, age, education and years of service in a basic model (Model A). A subsequent model assessed the influence of site as a proxy of ethnic group, after adding the site variable to the model with pre-intervention knowledge, in addition to any significant predictors of knowledge gain from Model A (Model B). Additional variables were then added to Model B separately in a series of models as part of an exploratory analysis (being in a stable partnership, having children, having dependents and having a medical condition) (Models C-F).

Model A: Only pre-intervention knowledge and highest level of education were significant predictors of gains in accuracy in diagnosing disorders following the intervention. A CHW who was able to correctly diagnose one additional disorder at baseline had approximately a fourfold reduction in the likelihood of gaining in accuracy after the intervention, after adjusting for differences in age, education and years of service (Odds Ratio (OR) = 0.217, 95% CI = 0.085 - 0.552,  $p = 0.001$ ). An increase in the highest Grade of education by one year was associated with more than doubling the odds of showing an improvement in correctly diagnosing the disorder in the vignettes (OR = 2.159, 95% CI = 1.081 - 4.315,  $p = 0.029$ ), after adjusting for the other covariates.

Model B: Adding site to the resulting model with pre-intervention knowledge and HLOE as predictors revealed a trend toward a site difference in the likelihood of improvements in gaining knowledge (Deviance score = 3.666,  $p = 0.056$ ). Inspection of the summary statistics by site reveals a marginally larger proportion of improvers at OTSM than Masincedane (64.3% versus 61.1%), with the site-effect probably due to the lower education and higher pre-intervention knowledge at OTSM the effects of which were adjusted in Model B (these differences in site were significant for pre-intervention knowledge only, Mann-Whitney  $Z = -2.4325$ ,  $p\text{-value} = 0.015$ ).

Models C-F: Of these models, which included additional variables separately as predictors to Model B (including the site variable), only having dependents was associated with greater odds of improving diagnosis post-intervention, with an additional dependent being associated with a 31.3% reduction in the odds of improving in knowledge. Model E (with the dependents as an additional variable) represented a significant better fit of the data than Model B (Deviance score = 4.506,  $p = 0.0338$ ). The rest of the quantitative outcomes are presented Table 4-2.

**Table 4-2 CHW Training Quantitative Outcomes**

Outcome	Pre-training (mean, SD, N)	Post-training (mean, SD, N)	Statistic (df)	p-value
Knowledge				
(MAKS)	41.48 (5.85), N=58	45.57 (4.25) N=56	$t = -4.523, (55)$	< 0.001
Confidence				
(MHNCCS)	45.25 (9.97), N=58	61.75 (7.42) N=54	$t = -8.749, (54)$	< 0.001
	Pre-training (mean, SD) N=45	Post-training (mean, SD) N=45		
Attitudes (CAMI)				
Authoritarianism	27.87 (2.97)	26.38 (4.1)	$t = 2.720 (44)$	0.99
Benevolence	37.67 (4.46)	38.82 (3.79)	$t = -1.818 (44)$	0.04
Social Restrictiveness	24.73 (4.28)	22.4 (5.3)	$t = 2.96 (44)$	0.002
Tolerance to rehabilitation in the community	36.49 (5.11)	38.09 (4.22)	$t = -2.18 (44)$	0.02

Analysis models are detailed in text

**MAKS:** There was a significant increase in the average scores on the MAKS pre- to post-training for 56 participants, as determined using a within-subjects t-test:  $t = -4.523, df = 55, p < 0.001$ . This difference remained when comparing the post-assessment and 3-month



assessment scores (mean 45.67, SD 4.59,  $t = -5.0$ ,  $df = 53$ ,  $p < 0.001$ ,  $N = 54$ ). A qqplot indicated substantial departures from normality for the residuals of Model A. This was addressed by removing data from three participants who were outliers with respect to various measures (as much of their data was missing post-training), including standardized residuals and Cook's distance. After their exclusion, the model residuals indicated some degree of non-normality, but this was judged as acceptable. Model A: The only variable that was significantly associated with change in knowledge on the MAKES pre-and post the training was the pre-training MAKES score and the highest level of education. An increase of one point at baseline on the MAKES was associated with a decrease by close to 1 point in changes on the MAKES associated with the training (coeff -0.837,  $t = -7.506$ ,  $p < 0.001$ ), after adjusting for differences in age, education and years of service. An increase in the highest Grade of education by one year was associated with a relative increase by more than 1 point on changes in MAKES scores (coeff = 1.106,  $t = 2.433$ ,  $p = 0.019$ ), after adjusting for the other covariates. Model B: Adding site to the resulting model with pre-training knowledge and HLOE as predictors did not provide any evidence of a site effect. Models C-F: Of these models, which included additional variables separately as predictors to Model B (excluding the site variable), only having a stable partner (Model C) was associated with a change in knowledge. CHW in stable partnerships demonstrated an increase in knowledge on the MAKES of over 2 points relative to individuals who were not in such relationships (coeff = 2.142,  $t = 2.035$ ,  $p = 0.047$ ).

#### **4.3.2.2 Confidence**

There was a significant increase in the average scores on the CONF questionnaire pre-to post training for 54 participants, as determined using a within-subjects t-test:  $t = -8.749$ ,  $df = 54$ ,  $p < 0.001$ . Four subjects were removed due to missing data. A qqplot indicated that distributional assumptions of normality were upheld.

Model A: The only variable that was significantly associated with change in the confidence score pre-and post the training was the pre-training confidence score. A CHW with one extra point on the confidence scale at baseline demonstrated a reduction in change in confidence after the training by more than point (coeff -1.150,  $t = -10.981$ ,  $p < 0.001$ ), after adjusting for differences in age, education and years of service. A statistical trend was also observed for age, with each additional year associated with a reduction in gains in confidence post training (coeff = -0.177,  $t = -1.875$ ,  $p = 0.067$ ). Model B. Adding site to the resulting model with pre-training confidence scores and age as predictors did not provide any evidence of a site effect.

Models C-F: Of these models, which included additional variables separately as predictors to Model B (excluding the site variable), a trend towards a significant effect on changes in confidence pre-post training was observed for both being in a stable partnership ( $p = 0.089$ ) and having a medical condition ( $p = 0.055$ ). Having a medical condition was associated with a decreased gain relative to someone without a condition in the effect of the training on confidence (coeff = -4.845,  $t = -1.969$ ,  $p = 0.055$ ), whereas being in a stable partnership was associated with an increased gain in confidence relative to someone without a partner, of approximately three and a half points on the CONF (coeff = 3.424,  $t = 1.736$ ,  $p = 0.089$ ), after adjusting for differences in the covariates age and pre-training confidence.

#### **4.3.2.3 Attitudes**

The negative items of the CAMI were reverse-scored by subtracting each item's score from the maximum score possible +1, as this is standard practice. In the case of the CAMI, the max score + 1 = 6, so if a negative item is scored 2, this procedure will result in a score of 4 (6-2). The negatively and positively worded items were then added up for each cluster to get a total score for each. The data from thirteen participants were removed, as

a substantial amount of data was missing for the pre-training variables in particular. The total sample for the CAMI analyses was therefore 45.

**Authoritarianism:** There was no evidence of a change in scores following the training, as revealed by a paired t-test:  $t = 2.720$ ,  $df = 44$ ,  $p\text{-value} = 0.995$ . Model A: The only variable that was significantly associated with change in attitudes for the authoritarianism cluster pre-and post the training was the corresponding pre-training authoritarianism score. An increase in scores at baseline was associated with a decrease in score changes associated with the training (coeff= -0.401,  $t = -2.054$ ,  $p = 0.047$ ), after adjusting for differences in age, education and years of service. Model B: Adding site to a model that included only pre-training scores as a predictor of changes on the authoritarianism cluster failed to detect a site effect (coeff = -0.427,  $t = -0.365$ ,  $p = 0.717$ ). Models C-F: None of the additional covariates significantly predicated changes in attitudes on the authoritarianism cluster when added to a model including pre-training CAMI score.

**Benevolence:** There was a significant increase in scores following the training, as revealed by a paired t-test:  $t = -1.818$ ,  $df = 44$ ,  $p\text{-value} = 0.0379$ . Model A: The only variable that was significantly associated with change in attitudes for the benevolence cluster pre-and post the training was the corresponding pre-training benevolence score. An increase of one point at baseline was associated with a decrease by more than half a point in changes associated with the training (coeff = -0.597,  $t = -4.919$ ,  $p < 0.001$ ), after adjusting for differences in age, education and years of service. Model B: There was a trend towards a site-effect on changes on the benevolence cluster score, after adjusting for differences in the pre-training scores for this cluster (coeff = 1.9897,  $t = 1.887$ ,  $p = 0.066$ ). This was due to an increase in scores on this cluster for the OTSM site only (mean = 1.81,  $SD = 4.6$ ,  $N = 31$ ), with minimal change observed in the Masi site (mean = -0.29,  $SD = 3.07$ ,  $N = 14$ ). Model C-F: Of these models, which included additional variables separately as predictors to Model B (including pre-training score and group, but excluding the site

variable), only having one's own medical condition (Model F) was associated with a change in benevolence attitudes. CHWs with their own medical conditions displayed an average change in scores of more than 4 points lower than those without medical conditions on this cluster (coeff = -4.273,  $t = -4.620$ ,  $p < 0.001$ ), after adjusting for pre-training scores and differences between groups in change scores. This was due to an increase in scores on this cluster for those without medical conditions only (mean = 2.19, SD = 4.25, N = 31), with minimal change observed in those with medical conditions (mean = -1.14, SD = 3.39, N = 14). This was observed even though most of the people with medical conditions (13 of 14) were in the OTSM group, which actually demonstrated increased changes pre-post training. The change in score is substantially higher in the OTSM group (mean = 3.89, SD = 4.2, N = 18) than the Masi group (mean = -0.15, SD = 3.16, N = 13) when people with medical conditions are removed.

***Social restrictiveness:*** A one-tailed paired t-test of the prediction that the training would result in a decrease in scores on the social restrictiveness cluster was supported ( $t = 2.960$ ,  $df = 44$ ,  $p\text{-value} = 0.002$ ). Model A: The only variable that was significantly associated with change in attitudes for the social restrictiveness cluster pre-and post the training was the corresponding pre-training score. An increase of one point at baseline was associated with a decrease by close to half a point in changes associated with the training (coeff = -0.437,  $t = -2.525$ ,  $p = 0.016$ ), after adjusting for differences in age, education and years of service. There was also a trend towards a reduction in scores post-training in CHW's with more years of service (coeff = -0.684,  $t = -1.852$ ,  $p = 0.071$ ). Model B: There was no site-effect on changes on the social restrictiveness cluster score, after adjusting for differences in the pre-training scores for this cluster and the effect of service duration (coeff = 0.0302,  $t = 0.019$ ,  $p = 0.985$ ). Model C-F: Of these models, which included additional variables separately as predictors to Model B (excluding the site variable), only having a medical condition (Model F) was associated with a change in attitudes. CHW with

medical problems changed their responses to a greater extent following the training (coeff = 3.2624,  $t = 2.083$ ,  $p = 0.0436$ ). A substantial reduction in score was only observed in CHWs without medical conditions (mean, SD = -3.35, 5.17), compared to those with medical conditions (mean, SD = -0.07, 4.98).

***Tolerance to rehabilitation in the community (CHMI)***: There was a significant increase in scores following the training, as revealed by a paired t-test:  $t = -2.176$ ,  $df = 44$ ,  $p\text{-value} = 0.018$ . Model A: The only variable that was significantly associated with change in attitudes for the CMHI cluster pre-and post the training was the corresponding pre-training score. An increase of one point at baseline was associated with a decrease in change associated with the training (coeff = -0.621,  $t = -5.478$ ,  $p < 0.001$ ), after adjusting for differences in age, education and years of service. Model B: There was no effect of site on changes on the CMHI cluster score, after adjusting for differences in the pre-training scores for this cluster (coeff = 0.754,  $t = 0.602$ ,  $p = 0.551$ ). Model C-F: Of these models, which included additional variables separately as predictors to Model B (excluding the site variable), and adjusting for baseline scores, none of the addition predictors (stable partnerships, having children, having dependents, and having own medical conditions) predicted changes pre-post training on the CMHI cluster. There was a sub-threshold effect for having a medical condition, though, with those with a condition demonstrating a reduced change in scores post training (coeff = -2.105,  $t = -1.760$ ,  $p = 0.086$ ).

#### **4.3.3 Qualitative**

Several themes emerged from the daily evaluation forms. Participants reported finding the content easy to follow and understand. Six participants indicated that certain aspects of culture and cultural idioms were not fully understood.

*“About the Xhosa paying the Lobola<sup>a</sup>” (OTSM 30)*

*“The putting of money on a handkerchief while you are taking it from somebody”*

(MS 11)

*“The difference between culture and religion of can be tricky” (OTSM 20).*

*“The meaning of culture the names in Xhosa” (OTSM 25)*

*“Yes lik cultural idioms yoh I don’t know these things” (MS 20).*

Two participants also mentioned being uncertain about the best way to interact with people with mental illness. Participant MS 15 and OTSM 30 reported respectively:

*“How to behave next to a mental illness person” (MS 15)*

*“That people have that disease still looks normal and can do normal things still”.*

(OTSM 30)

At the end of Session 3, participants indicated that more information was required about bipolar mood disorder and depression.

*“Yes, Bipolar Mood Disorder. The name I never heard of it” (MS 3).* Three participants specified that more information regarding depression is needed.

*“Depression is it the same as stress?” (OTSM 10).*

*“I want to learn more about depression” (MS 4).*

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<sup>a</sup> Lobola is a dowry paid by the groom’s family to the bride’s family to cement ties before a marriage can take place.

At the end of session 4 one participant expressed not having an understanding of behaviour they had observed from the elderly while another felt the session had been too short.

*"The things the old people do or think" (MS 11)*

*"... just time was too short" (OTSM 25).*

Two dominant themes emerged from most of the sessions, namely (1) expressing gratitude, and (2) emphasizing positive features of the session.

The participants expressed their gratitude towards the facilitators for their efforts in presenting a session that was experienced as valuable and worthwhile.

*"Thank you. It helps a lot" (MS 15)*

*"learning a lot every time I'm here thank u" (MS 3).*

*"I've learn today. Thanx." (MS 27).*

*"Just to day thanks for everything" (MS 18).*

*"for putting lot of information, knowledge & skill on me!!!" (MS 14) and*

*"thank you for opening my eyes" (MS 24).*

*"... enjoyed it a lot. Thank you" (OTSM 23). "Thank you [facilitator's name] for your time and effort, thank you for teaching me so much" (MS 19). "Thank you for this session eye opener" (MS 24).*

The information being presented was experienced as informative and interesting.  
CHWs could develop a better understanding regarding mental illness.

*“Lovely session keep it up” (OTSM 24)*

*“I loved it” (OTSM 23)*

*“very interesting and informative” (OTSM 20).*

*“Please dont stop to us go forward” (MS 8).*

*OTSM 20 and OTSM 9 respectively:*

*“The session was very good 😊” and*

*“Enjoying this training very much”.*

*“learn’t alot” (MS 27)*

*“I learned alot about everything”. OTSM 25*

*“The lesson was very interesting” (MS 21). From the training, For example, a person  
with depression –*

*“It helped me understand better about suicidal person's feelings” (OTSM 16).*

The content was perceived as important and applicable to the field of practice and  
as such, was viewed as likely to help the CHW’s make a meaningful contribution to their  
communities.

*“I enjoy this session it is very important to know everything” (MS 20).*



*“Was very helpful. I feel I can really be of help in our community” (OTSM 2).*

*“It is a very good lesson to us as we live in places where there is a lot of people who use substance abuse but we couldn’t help because of lack of knowledge” (OTSM 24).*

*“I feel educated enough to be of help for some-one in need”.*

*“It was a learning session and have a good information for me. I will apply in my community and my family”. (MS 9)*

*“Just to share our different experience in our work and community”, (OTSM 7)*

*“I feel more confident” (OTSM 2).*

Some participants found the volume covered in this session overwhelming.

Participant MS 2 and MS 9 explained:

*“It was a lot but interesting” (MS 2)*

*“It was a challenge session to learn and get more knowledge”. (MS 9)*

Participants felt that the information had been presented in a clear and simple way by the facilitators,

*“...very clear and simple” (MS 10),*

Some participants mentioned that the session was also *“...very emotional” (OTSM 7)* and *“It open close wounds” . (OTSM 25)*

In Session 5 participants reported benefitting most from (1) education on substance abuse, (2) additional psycho-education, (3) engagement and emotional involvement.

*“Learning more about substance abuse” (OTSM 24).*

*“I enjoyed the sessions about all three substance use disorders...” (OTSM 22).*

This does not only include *“learning about the different types of substance abuse”* (OTSM 4), but also *“the effect it has on an individual”* (OTSM 15) such as *“withdrawal symptoms”* (OTSM 8) and the *“side effects of the drugs”* (OTSM 18). It emerged that dealing with substance abuse involves a significant part of the CHWs field of work, an area where they felt they could make an impact by assisting and supporting the people within their communities. Two participants reported they would like to get more education about substance use disorders. It is not clear from the data whether these two participants did not understand certain aspects or whether they merely wished that the duration and the content of the training programme focused more on these.

*“I’m happy about today’s lesson because a lot of people are involved in substance abuse and it affects our communities as well”* (MS 24).

*“That this session help us to educate our elderly client how to deal with their substance abuse children”* (OTSM 17).

*“I would like to be given more time and more information on substance abuse and their symptom and their long term illnesses”*. (MS 24)

*“More and more about the types of drugs”*. (MS 4)

Participants expressed finding value in learning more about mental disorders and their management.

*“How to manage some one with disorders...”* (MS 18).

*“... I have enjoyed mental disorders and the management”* (OTSM 19).

*“The treatment of different illness” (OTSM 31)*

*“medication about depression etc.” (MS 9)*

The benefit of receiving information on other topics such as motivation and stress management was also mentioned.

*“I’ve enjoyed a lot the part of motivation. How to motivate someone” (MS 27).*

*“Enjoy the most to day is to now how to deal about stress manager” (MS 8).*

Engagement and emotional involvement of the group was one of the reasons why they enjoyed the session. The sharing of their own narratives helped participants learn from each other.

*“The sharing of experiences from the group” (MS 16).*

*“Enjoying sharing the experience of group” (MS 22).*

*“By hearing different stories although some was very sad but at least I gain something and knowledge”. (MS 13)*

Participants valued the discussion of the role of the CHW in the community. By sharing stories and narratives within the group regarding their experiences and duties as health workers in the community, participants could learn and gain valuable advice from each other. Participants felt reminded not only of the importance of their work in the community, but also about the responsibility that comes with it. As a result of this engagement process, re-identifying their role in the community, participants could felt they could once again gain meaning necessary to stay inspired and dedicated.

*“Enjoy because we talking our role in a community” (KH 20)*

*“Sharing the experiences that we come across with the mental illness people and what to do.” (MS 11)*

*“I’ve learned that there are more roles to community caregiver then I thought” (OTSM 03).*

*“Reminder of the community health care workers responsibilities” (MS 25).*

*“How most of what we do on daily life is what most people need” (OTSM 2)*

*“...just to listen to them give me strength” (MS 20) –*

Participants identified acquiring counselling skills as one of the main reasons they enjoyed the session. They felt empowered to bring about a real difference in their work environment.

*“I enjoy the support and counselling skills” (MS 2)*

*“I enjoy the lesson because I can go speak in the community to listen to them to counselling them about things I learn” (OTSM 11)*

Participants experienced it as inspiring and informative to have the opportunity revise the content of previous sessions.

*“I enjoy the session about reflexion about the previous work” (OTSM 20).*

*“Whas very informative about all of the previous work that we did” (MS 10).*

### *Training evaluation questionnaire*

The training programme was well received by the CHWs. Overall the majority of the participants expressed their gratitude and requested that the programme must continue. *"Thank you it was nice having this class"* (MS 15). *"I would like the training to continue I enjoyed every session"* (OTSM 22). *"I wish we can have more training like this in our communities"* (OTSM 7). Their positive experience can be attributed to several factors. Firstly, the participants perceive the content of the training as informative and stimulating, as reported by participant OTSM 15: *"The eight week training was very informative. I have learnt quite a lot. Enjoyed every second"*. Furthermore, the content was recognized as highly applicable to their practice (*"I learned a lot to help me in the community"*, KH 20). The participants are better equipped and feel more confident to do their work as described by participant OTSM 7: *"I am empower to be more effective in my community"*. As such participants can make a meaningful contribution in their communities (*"...knowing I would give some away what I've Learn't"*, MS 27). This programme also facilitated to change the participants' perceptions of people with mental illness, as illustrated by participant OTSM 27 and OTSM 25 respectively: *"...looking at people with a different eye"* and *"now I am open minded in situations"*.

The delivery of the training itself was regarded as effectively accomplished (according to facilitator appraisal). The facilitators created a comfortable environment and maintained clear communication. *"Felt comfortable & at ease"* (OTSM 31). *"Trainer very well spoken and knew exactly what she was talking about so I felt very comfortable in sharing my exsperiences with her"* (MS 16). The participants experienced the use of examples during the training programme as particular useful, as demonstrated by participant OTSM 9: *"...examples given while doing training only makes us understand better"*. Overall the

content was perceived as well presented by the participants, as illustrated by participant MS 10: *“all topics covered whas whell presented by facilitator”*.

A few suggestions were made on behalf of the participants regarding the training. Two participants mentioned that they would like to learn more about intellectual disability. *“I would like to learn more about Intellectual disability”* (MS 3). Some participants also commented on the length of the duration – wishing the duration of the training was longer. *“The course was very helpful but I think I need more”* (MS 11). *“Was a bit short”* (OTSM 10). Participant MS 18 summarised: *“If we had more time, I Think I can learn alot more. Because in our community there are alot of mental health problems and every one is not the same”*. One of the participants also suggested that information pamphlets should be handed out after the case studies. *“I just wish that were given pamphlets as a reminder on each case study”* (MS 24). It would indeed be beneficial to hand out study material which can be applied for future reference.

#### **4.3.4 Training evaluation**

There was very little variability in the subscale scores for the different Training Evaluation components, making it difficult to detect associations between covariates and scores on these subscales. There were additionally no group differences identified.

The means and standard deviations for the subscales are displayed in Table 4-2 below, as well as the proportion of the 54 CHWs with data for 2017 who provided the maximum score on each subscale.

**Figure 4-11 The trainer, Mrs. Lezel Molefe at Caring Network Khayelitsha**



Mrs. Molefe is a social worker in private practice in Cape Town. She developed and delivered the original training at New Beginnings, and has experience with training and group facilitation.

**Table 4-3 Training Evaluation**

Component satisfaction	Max Score	Total (n=58)		Masinedane (N = 31)	OTSM (N = 27)
		Mean score (SD)	% with Max Score	Mean score (SD)	Mean score (SD)
Overall	15	13.98 (1.35)	61.1%	12.44 (4.34)	13.71 (2.4)
Training Benefit	15	13.85 (1.41)	53.7%	12.26 (4.3)	13.65 (2.4)
Training Processes	15	13.57 (1.4)	42.6%	12.15 (4.55)	13.16 (2.37)
Training Setting	10	9.06 (1.14)	51.9%	8.04 (2.88)	8.94 1.59
Training Content	25	22.17 (2.65)	31.5%	19.37 (7.39)	21.9 (4.12)
Trainer	30	28.07 (2.58)	55.6%	25.07 (9.02)	27.35 (4.73)

## 4.4 Discussion

Our main findings were 1) an overall improvement in knowledge as demonstrated by improved diagnostic accuracy and MAKS scores; 2) improvement in confidence and 3) an overall positive change in attitudes, amongst the trained CHWs in all but the

authoritarianism subscale, 4) satisfaction with the content and processes of the training and expression of sentiments of gratitude and feeling empowered.

There is little work on the efficacy of community health worker training programmes (Liu et al., 2016). The improvement in diagnostic accuracy at the end of this training programme is consistent with the findings in one similar study (Armstrong et al., 2011). Previous work has suggested CHW performance is associated with age, sex, education level, years of service (experience), marital status, and financial status (Kok et al., 2015). In our sample, higher pre-training knowledge reduced the likelihood of significant improvement in knowledge, while highest level of education was significantly associated with the likelihood of improvement in knowledge. This highlights the importance of taking into account basic training requirements and trainability for CHWs (Kawakatsu et al., 2015). CHWs at one site showed marginally better improvement, possibly as a consequence of pre-training knowledge attained in the course of standard NPO training activities.

Confidence scores increased significantly following the training. There was an overall positive change in attitudes in all but the authoritarianism subscale. Higher scores on the authoritarian attitudes have previously been linked with prevailing societal stigma related to perceived danger from people with mental disorders (Aznar-Lou, Serrano-Blanco, Fernández, Luciano, & Rubio-Valera, 2015). This perceived danger is likely related to the perceived unpredictability and occasionally violent nature of psychiatric presentations (Shrivastava, Bureau, & Johnston, 2012). The overall decrease in stigmatizing views and the improved confidence matched the findings of the abovementioned study (Hofmann-Broussard, Armstrong, Boschen, & Somasundaram, 2017). Other studies of community and health worker attitudes towards the mentally ill have suggested that attitudes supporting social integration may be related to mental health training and experience, and linked to a grasp of the biopsychosocial causation of mental illness (Sun et al., 2014; Wolff, Pathare,



Craig, & Leff, 1996). The need for training that includes a focus on biopsychosocial causation was born out in a Nigerian study evaluating attitudes and beliefs about mental illness amongst church-based lay health workers (Iheanacho et al., 2015). Respondents in this study widely held stigmatizing culture-bound concepts as causative for mental illness. Our training began by engaging with such local beliefs before introducing the biopsychosocial discussion, and this appears to have gone some way towards improving attitudes amongst our participants. Having said this, it is worth noting that stigmatizing attitudes towards mental illness, such as authoritarianism, are difficult to change (Casados, 2017). Much work is required to focus the research agenda in the field to adequately address this. CHWs having their own medical illness was associated with decreased gains in confidence and attitude. This finding suggests a need for more focused investigation of the impact that having a chronic medical illness may have on attitudes towards mental illness and MHSU, as well as on confidence in executing support roles.

There were high level of satisfaction with the training. The qualitative assessment elicited themes of gratitude and appreciation for the processes and content of the training. CHWs felt that the training would assist them in improving the quality of their contribution to their communities. This altruistic sentiment of CHW's desiring to do more for their communities has been noted before, where the Christian ethic of care alongside the concept of "Ubuntu", which refers to the African concept of community, have navigated an uneasy tension with the CHWs own socioeconomic struggles and needs (Swartz & Colvin, 2015). CHWs expressed areas in which further training would be desirable, and these included the areas of substance use disorders, bipolar mood disorder and geriatric psychiatry.

## **4.5 Limitations**

A first limitation is that this investigation was not controlled. I felt this was acceptable as this is a preliminary study, the findings of which might inform a future RCT.

The findings of this study must therefore be considered with caution as causality of effect may not be directly inferred. A second limitation is that MHSU-level outcomes were not evaluated. While changes in knowledge, confidence and attitudes are necessary for improvements in care for MHSU they are not necessarily a sufficient condition for improved community-based care for MHSU.

## **4.6 Conclusion**

This community health worker training intervention succeeded in improving knowledge, confidence and attitudes amongst the trained CHWs. Participant feedback indicated that the training was acceptable, while high attendance and stakeholder buy-in pointed to feasibility and the potential for engaging CHWs in delivery task shifted mental health care. In spite of these encouraging preliminary results, further controlled trials are warranted to assess MHSU-level outcomes.

## **Chapter 5 Discussion and recommendations**

This PhD sought to characterise the evidence for task shifting interventions in Sub-Saharan Africa, and to then pilot and evaluate the acceptability, feasibility and preliminary efficacy of two such interventions. Here the findings for each investigation are summarized, followed by a discussion of some of the factors that impacted on the delivery of these. Recommendations for future research are then provided.

### **5.1 Summary of findings**

#### **5.1.1 Systematic review**

In the systematic review, half of the included studies made use of the RCT design in the testing of mental health interventions delivered by non-specialist health workers. Current evidence points towards some promise for their efficacy. Interventions were largely focused on depressive illness and anxiety. Methodologies and outcome measures used were disparate, indicating a heterogeneity that continues to limit trial comparability. The discussion and recommendations which follow will shed some light on some important considerations in the planning of investigations of non-specialist-delivered interventions focused on adherence support for severe mental illness in a setting such as ours.

#### **5.1.2 Task shifting interventions**

All the components of the treatment partner and m-health intervention were acceptable, and all but the m-health component were feasible. The CHW training intervention was acceptable and feasible. Although the sample size in the RCT limits the generalizability of secondary efficacy findings, both interventions demonstrated findings in favour of the intervention. While authoritarian attitudes were not shifted, the CHW training

in particular yielded significant positive outcomes with improvements in knowledge and skill, along with improvement in confidence and attitudes. This is good news for our resource-strapped setting, and is in keeping with previous literature (van Ginneken et al., 2013b).

Factors impacting on my investigations included those related to the individual participants and the interventions, as well as wider social issues. Stakeholder participation was a significant factor in the success of components of interventions, from planning to execution, while unemployment, poverty, crime, and technological issues presented some challenges which future investigators will need to keep in mind.

## **5.2 Factors impacting on investigations and findings**

### **5.2.1 Stakeholder participation**

Stakeholder involvement refers to the involvement of service users, health care personnel, families and caregivers, government personnel, policymakers, and all relevant parties involved in health decision-making in research, from research design to implementation and sharing of results (Fuster et al., 2014). This is an important aspect of ensuring the acceptability and trustworthiness of intervention research, with even stakeholders not directly involved in the delivery of health services providing input pertinent to the successful translation of research (Brooks, Sanders, Lovell, Fraser, & Rogers, 2015), with interventions and products which are more relevant to the parties who are most likely to be directly affected (National Institute for Health and Care Excellence, 2013). It was for these reasons that stakeholders were involved in the design and implementation of my investigations.

#### ***MHSU and Caregivers***

During the development phase of the treatment partner intervention, it was important to involve the role players involved in treatment adherence, as well as in

adherence and social support for MHSU. MHSU involvement began at development stage during focus group and in-depth interviews (Mall et al., 2013). MHSU involvement in mental health system development is supported by MHSU and caregivers, and has the potential to not only empower MHSU through involvement in the development of systems for their own care, but also to developing more appropriate and acceptable approaches to mental health priorities such as adherence (Abayneh et al., 2017). The benefit and ultimate role adopted by MHSU is determined by the needs of the researcher, which have to be clearly developed in order to maximize benefit (Staley, Kabir, & Szmukler, 2013). For this PhD, MHSU were involved from the qualitative investigation conducted at intervention-design stage. Most researchers find this stage of involvement most challenging for various reasons including ethics and funding submission deadlines (Staley, Kabir, & Szmukler, 2012). Caregivers of MHSU were involved at intervention-design stage as well (Mall et al., 2013). Their participation through focus group and in-depth interviews, extended into the active role of treatment partner and caregiver as described in Chapter 3.

Other more involved roles for MHSU include input for study design and processes, and as research staff. These were outside of the scope of needs for my project. It remains to be seen however, whether MHSU and caregiver involvement actually results in the strengthening of mental health systems (Semrau et al., 2016).

### ***Mental Health nurses and NPOs***

Mental health nurses and social support NPO's providing mental health social support for MHSU and their families, were also an integral part of the interventions in this PhD. The mental health nurses participated as fieldworkers in the intervention, as described in Chapter 3. The NPO's which are included in study setting description in Chapter 3 play several roles matching those described by Kleintjes et al, including advocacy work aimed at de-stigmatization of mental illness and protection of MHSU rights; facilitation of access to

mental health care; programmes to aid with socioeconomic reintegration and growth; contribution to policy reform and capacity building (Kleintjes, Lund, & Swartz, 2013). These NPOs were engaged at the design phase of the intervention. An appraisal of the specific services offered by each was performed, and these were included in the psychoeducation component. While MHSU and caregivers were made aware of these services in this way, it was more important to ensure that the mental health nurses were fully aware of the same services and appropriate pathways to access them. For this reason, the mental health nurses were present during my engagement with NPOs, and were able to gain awareness and clarity in this regard.

### ***Clinicians***

In spite of evidence that participation in research improves healthcare performance while increasing the evidence base for care (Boaz, Hanney, Jones, & Soper, 2015), clinicians are generally understood to be averse to clinical research activities for a number of reasons (M. K. Campbell et al., 2007). It has been viewed as a distraction from clinical duties and having no impact on immediate service delivery, while at the same time adding burden to already busy clinical duties. There has been concern that research may harm health service users by withholding treatments during the conduct of research (Freeman et al., 2015). Engaging with clinicians from the outset and keeping them fully informed of study protocols and developments, while making efforts to align the research agenda with desired clinical outcomes, can go some way towards addressing many of these concerns (Paget, Caldwell, Murphy, Lilischkis, & Morrow, 2017). At the same time, it is important for research activities to be designed to impact minimally if at all, on clinical services. Human Research Ethics Departments are tasked with protecting participants from harm, and clarifying this role to clinicians is a crucial step (World Health Organization, 2011).

In facilitating collaboration between researchers and clinicians (Paget et al., 2017), clinician involvement at VBH began with the input into the psychoeducation component of the intervention. Specialist psychiatrists reviewed and made content suggestions during the development of the psychoeducation guide. This created a collaborative environment that saw research activities being viewed positively, with a few clinicians actively referring potential participants to the study. Clinicians were kept abreast of research activities through occasional feedback in clinical meetings.

### ***Western Cape Department of Health***

Researchers and stakeholders have been found to have congruent priorities, which are in line with disease burden estimates and in turn match researcher projects (Sharan et al., 2009). Perceptions of the extent to which researcher interest determines project prioritization are mixed, which drives home the importance of dialogue and collaboration with stakeholders (Innvaer, Vist, Trommald, & Oxman, 2002).

To this end, the Western Cape Department of Health (WCDoH) was involved in the development and delivery of the CHW training intervention. The WCDoH was involved with the conceptualization of the training from the outset. Following a series of meetings in which training needs were communicated by the department, the processes of development were initiated, as described in Chapter 4. WCDoH role players involved ranged from the mental health programme director to social workers within the department, and included clinicians involved in mental health care delivery in the sub-districts. The consistent open dialogue and feedback strengthened the processes of developing and piloting the training.

### **5.2.2 Unemployment and poverty**

In a recent South African psychiatric epidemiological survey mental illness was associated with reduced earnings by an estimated mean of \$4798 per year, an extrapolated

total earnings loss of \$3.6 billion for mentally ill South Africans (Lund, Myer, Stein, Williams, & Flisher, 2013). Available evidence currently fails to draw a correlation between poverty alleviation and mental, while treatment of mental illness is likely to improve the economic circumstances of MHSU (Lund et al., 2011). This highlights the potential wider economic impact of effective mental health intervention and treatment.

South Africa continues to experience high unemployment rates (27.7% in July 2017), with the number of unemployed rising by 433 000 in the first quarter of 2017 (Statistics South Africa, 2017a). Cape Town is home to 64.2% of the population of the Western Cape, and has an unemployment rate of 23.9%, impacting predominantly the black and coloured race groups, the predominant racial breakdown of the participants in my investigations. Some sectors such as clothing manufacturing and textiles are experiencing some growth, resulting in many instances of people having to leave their homes in search of employment (Western Cape Government Provincial Treasury, 2016). This trend saw a few of our treatment partners change, as individuals left home or relocated to look for work. With 35.7% of households living below the poverty line (less than R3500 per month), many Cape Town residents are living hand to mouth (Statistics South Africa, 2015).

These poor socioeconomic circumstances result in poor outcomes for MHSU, with poverty impacting on the presentation of mental illness, from increasing risk of mental illness to resulting in reduced socioeconomic activity either as a direct consequence of illness or due to exclusion (Lund et al., 2010). MHSU are often excluded from employment opportunities, thus sustaining the cycle of poverty that worsens clinical outcomes, which in turn deepens poverty (Lepiéce, Reynaert, Jacques, & Zdanowicz, 2015; Saraceno & Barbui, 1997; Trani et al., 2015).

The burden of poverty additionally impacts on the capacity of caregivers to provide support for MHSU in their care (Ae-Ngibise, Doku, Asante, & Owusu-Agyei, 2015; Goodman



Sibeko et al., 2016). The current economic outlook does not indicate that the situation will improve anytime soon, therefore the challenges emanating from unemployment and poverty are likely to continue to contribute to the social burden and clinical outcomes for MHSU. The consequences of unemployment and poverty, such as crime and low levels of education are likely to impact on components of interventions similar to mine.

### **5.2.3 Crime**

Unemployment and poverty have been linked to crime, which remains a major challenge in South Africa (Bhorat, Lilenstein, Monnakgotla, Thornton, & van der Zee, 2017). Burglary accounts for 53% of all crimes experienced by households, with robbery affecting 10% of all South African households (Statistics South Africa, 2017b). The prevalence of robberies outside the home is highest in the Western Cape, with a majority (61,2%) of robberies occurring in a residential street, while 6,3% occurred in the workplace. Crime rates have been noted to rise in the Western Cape, with mobile phones and accessories remaining popular targets, making up 51,4% of items stolen from individuals, with 50% of robberies at clothing retailers targeting mobile phones (Crime Registrar, 2016). Some of the intervention participants lost their mobile phones through theft, while two of the fieldworker handsets used by the mental health nurses were stolen, one from the clinic and one while the nurse was in public transport on her way home from the clinic. Robbery is considered an important contributor to other contact crimes (Crime Registrar, 2016). While no projections are readily available for the outlook on crime statistics, there has been much consideration of the factors related to and contributing to crime. These include the socioeconomic factors discussed above, substances, and the availability of firearms. Crime therefore remains an important consideration in the conduct of research investigations in our context for the foreseeable future. The safety of research equipment and staff should be a serious consideration in the design of interventions. The choice was to make use of

affordable handsets which are easily replaced, with a functionality that does not stretch to many social uses. Larger studies may need to consider the inclusion of insurance cover for these components, while a consideration for security personnel could be applicable where there is a specific need and funding allows.

#### **5.2.4 Level of education**

My treatment partner intervention did not investigate the association of participant level of education with levels of insight and adherence efficacy outcomes. However, previous literature has shown that higher level of education may increase the likelihood of seeking mental health assessment and care (Steele, Dewa, Lin, & Lee, 2007). Having obtained a higher education level is likely to indicate better premorbid function for MHSU, which in turn may explain the better treatment outcomes in this group (Irani & Siegel, 2006)p. This association however, while true in first episode psychosis, may not sustained as illnesses progresses. In the training intervention CHW's with a higher level of education were more likely to show improvement in knowledge following training. This finding in in keeping with the literature detailing the characteristics associated with CHW performance (Kok et al., 2015). This has implications for CHW selection and recruitment for organizations tasked with their management and training. It is important to recognize the ideal that CHW's should be recruited from and with the participation of the communities from which they originate (U Lehmann & Sanders, 2007). The Community Health Worker Management Draft Version 6 stipulates that level of education may not be used as a requirement for employment. The framework goes as far as to say that individuals with disability or who are illiterate should equally be admissible as CHWs (National Department of Health South Africa, 2009).

#### **5.2.5 Technology**

The mental health nurses in the treatment partner intervention experienced several challenges interacting with the text message platform. Several factors have been identified as challenges in the use of mobile health technologies, including the usability of the mobile devices, the integration and interoperability of intervention technologies, privacy and confidentiality, and reliability (Gurupur & Wan, 2017). The usability of technological components, beyond keeping in mind as simple as the size, design and colour scheme of the mobile device, requires the sense of effectiveness, efficiency and satisfaction an individual has in using these. The use of complex navigation approaches such as hyperlinks have to be taken into consideration in making the interface user-friendly.

The mental health nurses in the treatment partner and m-health intervention were mostly of advanced age. Older adults are less likely to routinely interact with smartphones and other technology compared to younger adults (Czaja et al., 2006). This, together with “computer anxiety” may impact negatively on the ability of older people to interact with technology.

## **5.3 Way Forward**

### **5.3.1 Adherence support**

In settings such as ours where the socioeconomic circumstances may impact not only close family support, but also on the quality of community based support from CHWs, it is important to incorporate a design that empowers the MHSU in ensuring his or her own adherence behaviour. Interventions targeting medication adherence should ideally take into account issues of self-efficacy (Mall et al., 2013; McCann, Clark, & Lu, 2008). The self-efficacy model of adherence is focussed on the MHSU and recognizes the impact of the MHSU’s perception of the efficacy of the prescribed medication; ability to access mental health care and the quality of the MHSU’s relationship with mental health service providers; spousal or

family support; and supportive home and community environment (McCann et al., 2008). This socially inclusive approach has the added effect of promoting the recognition of MHSU as an important factor in his or her own adherence and recovery (Carter, Satcher, & Coelho, 2013; Collins et al., 2011; Jacobson & Greenley, 2001; Maj, 2011). Interventions focused on adherence may benefit from paying more attention to issues around attitudes to treatment as opposed to a focus on wider illness insight (Beck, Cavelti, Kvirgic, Kleim, & Vauth, 2011). This may help MHSU address concerns and nurture trust in pharmacotherapy, thus improving adherence.

Contributors to non-adherence, which require attention in such interventions, include structural barriers such as poor socioeconomic status and individual barriers such as poor health literacy and insight, male gender, substance misuse, and low social functioning (Nosé et al., 2003; Sorsdahl et al., 2012). Ongoing medication adherence monitoring and environmental support such as that provided by non-specialist workers has been suggested as an important programmatic approach for supporting medication adherence (Velligan et al., 2010).

### **5.3.2 Task shifting to non-specialist workers**

The non-specialist workers in the interventions included in the systematic review were largely drawn from the communities being studied, with strictly defined roles within the psychotherapeutic and manualized interventions delivered. This is in keeping with the suggestion that in order to be effective, it is crucial for CHWs to be actively embedded in the communities within which they work, and that the tasks assigned to them should be clear and focused, as opposed to being comprehensive and complex (Haines et al., 2007; Uta Lehmann & Sanders, 2007). CHW programmes which are embedded into the community have been noted to be more likely to yield positive feedback from members of the

community who's previously unmet needs were being addressed by such programmes (Kane, Gerretsen, Scherpbier, Dal Poz, & Dieleman, 2010). CHWs in turn felt more valued and more confident in their roles, with a sense of improved status within the community, especially in the context of structural support within the health system. This was echoed by the finding that CHWs enjoyed and found fulfilment in their role in the community, adding that the training would equip them to be better able to provide useful services within their communities. The hiring of the neediest members of the community; targeting of the poorest households; and proper service planning, including ensuring proximity to support services and supervision; are essential to ensuring equity of access and utilization of community health services (McCollum, Gomez, Theobald, & Taegtmeier, 2016). While the CHWs in my intervention are embedded and surrounded by support services, a current perhaps necessary limitation, is the need for all referrals to go via the NPO supervisor. While this limits the scope of their relationship to surrounding resources and services, it provides the role containment previously discussed as essential for the success of this level of task shifting (Haines et al., 2007).

In a recent review exploring factors impacting on the integration of CHW programmes into LMIC health systems (Zulu, Kinsman, Michelo, & Hurtig, 2014), only Brazil, Ethiopia, India and Pakistan had programmes which met the inclusion criteria, being that the programmes had to have been government-developed, with standardized supervision training programmes, and incentives for cadres. The Western Cape Government has shown initiative and investment in this by partnering with investigations such as my own, to develop a framework of more comprehensive training and supervision. Positive perceptions of the utility of CHW programmes, as well as policy-maker and community involvement in design and implementation processes were assessed as key factors in facilitating integration, a feature which bodes well for my training intervention. Programme integration into existing systems was additionally noted as enabling as it ensured that the programmes were

compatible. This integration remains a work-in-progress in our setting, as there is currently no direct line of communication or referral between CHWs and primary health and social services in our setting, as CHW's continue to report directly to their supervising NPO (U Lehmann & Sanders, 2007).

Factors which may inhibit the integration on CHW programmes include resistance from other health workers; too rapid a scale-up process; structural factors such as inadequate referral facilities; communication and supplies; and socioeconomic (Glenton et al., 2013; Zulu et al., 2014). These factors contribute to added risk for MHSU and CHW, as structural inadequacies often result in CHW going beyond the call of duty, often taking on tasks for which they have not received training or supervision (Ferrinho, Sidat, Goma, & Dussault, 2012). This improvisation has burden implications for primary care health staff as well, resulting in reduced work satisfaction.

In our setting, supervision of CHWs is provided by the NPO that employs them. Supervisors generally have a health service background, either as nurses or social workers, and are driven by the desire to extend themselves to the service of a community in need (Akintola & Chikoko, 2016). The roles of supervisors include immediate structural support for CHW programmes, including day to day management roles, as well as the provision of training and mentoring for CHWs. Their own remuneration and salary benefits serve as motivating factors in their work, while poor health service user outcomes, structural support deficits, job insecurity, and poor remuneration for CHWs and themselves act as demotivating factors (Akintola & Chikoko, 2016). This tension between altruistic motivation and job factors such as inadequate remuneration and career prospects has been highlighted previously (Mijovic, McKnight, & English, 2016). Also important to consider, is the impact of task shifting activities on all cadres within a health system, from whom tasks may be

delegated. Taking this into consideration may reduce the occurrence of resistance from other health care workers.

Task sharing as opposed to task shifting presents an approach which is likely to be more inclusive of other health care workers within a health system (Hanlon et al., 2016). In this approach the ongoing engagement of more specialized workers ensures improved and sustained support for cadres while encouraging system cohesion. The success of task sharing however, still hinges on the availability and or accessibility of more specialized cadres and resources. Technology remains a viable option to extend specialist support to primary care- and community-based cadres, while reiterating the need for training, adequate supervision and community partnerships for successful such interventions (Hoeft, Fortney, Patel, & Unützer, 2016).

### **5.3.3 M-health interventions in mental health interventions**

M-health interventions are promising in spite of the current dearth of evidence (Kauppi et al., 2014). Privacy and security are important considerations in the design of text message based interventions, particularly in vulnerable populations (Shivayogi, 2013). Text message encryption has been demonstrated to be both feasible and affordable and should be integrated in platform design (Hassinen & Laitinen, 2005). The field of m-health is expanding at a remarkable rate, possibly too fast for empirical research to keep up (Forrest et al., 2015). M-Health projects in Africa have thus far focussed on staff, data transfer and reporting, and supply processes (Kampmeijer, Pavlova, Tambor, Golinowska, & Groot, 2016), while the evidence for utility in Sub-Saharan Africa remains lacking (Aranda-Jan, Mohutsiwa-Dibe, & Loukanova, 2014). Telecommunications infrastructure challenges are another important consideration, in settings such as ours (Frost & Sullivan, 2017). The general lack of cost-effectiveness data, along with the resulting dependency on funding, and inconsistent

availability of infrastructure remain potential threats to the success of implementation of m-health programmes (Aranda-Jan et al., 2014). Indeed the large volume of m-health pilot trials need to be developed into full translational effectiveness trials in order to strengthen evidence (Bloomfield et al., 2014).

My investigation uncovered important practical issues that must be taken into account in the development of such interventions in our setting. The reality of crime resulting in risk of loss to participant handsets and platform utility for fieldworkers are important considerations that suggest the need for caution in the implementation of these interventions. The cost of developing simpler platform interfaces, as well as those associated with hosting of such platforms, is another limitation, which potentially poses a threat to the cost effectiveness of these interventions at present.

### **5.3.4 Mental health research**

#### **5.3.4.1 *Research priorities***

Evidence suggests that the most cost-effective way to improve access to care for MHSU is probably through the integration of mental health services into primary health care, while increasing access to screening, identification and early treatment for others at risk for mental illness (Jack et al., 2014). This was a key target of the community health worker intervention presented in Chapter 4.

The underspend on mental health services is echoed in the limited financial resources available for translational research in mental health. For example, research for depression is far less funded than is research for cancer, with approximately US\$5.3 billion been spent on cancer research in 2013 by the US National Institutes of Health (NIH), compared to \$415 million spent on depression, and \$2.2 billion on mental-health in general (Ledford, 2014). The same pattern holds elsewhere: in its most recently completed funding



scheme, the European Union invested about €54.3 million (US\$67.4 million) a year for studies of mental-health disorders, €8million of which was flagged specifically for depression. The programme allotted €205 million a year for studies of cancer.

As reflected in the findings of my systematic review in Chapter 2, a few gaps in knowledge have been identified as a focus for future research (Jack et al., 2014). These include the need for more comprehensive evaluation of the burden of mental illness, the development and testing of interventions integrating mental health services into current health systems, and the evaluation of the cost-effectiveness of interventions designed to address mental health concerns in a national context. There is a need for continued intervention studies such as the ones presented in this PHD, in LMIC, along with the socioeconomic consequences of scaled up mental health services, with evaluation of the impact of resource redistribution in mental health (Lund, De Silva, Plagerson, & Al, 2011).

#### **5.3.4.2 *Vulnerable populations and informed consent***

Vulnerable populations are broadly segments of the population who are disadvantaged in a way that puts them at increased risk for exploitation or abuse (Shivayogi, 2013; World Medical Association, 2013). Research on vulnerable populations such as MHSU and their families has previously been viewed as exploitative and lacking in clinical benefit for these populations, as findings were not seen to translate to clinical practice (Mabunda, 2001). However, excluding vulnerable populations from research potentially prevents them from obtaining benefit from these (Green, 2006). Translational research goes some way towards addressing these concerns by driving the focus of trials to comparative effectiveness in real world clinical settings (Chalkidou, Tunis, Whicher, Fowler, & Zwarenstein, 2012).

The Declaration of Helsinki provides some guidelines for the protection of vulnerable populations in research (World Medical Association, 2013). The responsibility to protect the

MHSU is placed on the physician, whose practice must be informed by the latest and best evidence-based treatments. Physicians are tasked with familiarizing themselves with the legal and procedural norms governing research, which should have minimal impact on the clinical environment and health services. Risk must be carefully considered and should not outweigh benefit in the delivery of an intervention. The clinical teams impacted by my interventions at VBH and within the sub-districts played a role in gatekeeping to ensure this protection for participants. Risk-benefit considerations must be presented to a research ethics committee, which in my case was the University of Cape Town Human Research Ethics Committee and Western Cape Health Impact Assessment Unit, whose role it is to assess the level of risk for the protection of study participants and continue to monitor ongoing studies.

Informed consent is key to rational decision-making and to protection of autonomy (Lidz, 2006). Participation in research must be voluntary with all studies activities fully explained and understood (Shivayogi, 2013; World Medical Association, 2013). This may be mediated by the extent to which important concepts of informed consent are understood, which may vary according to study setting and literacy levels (Afolabi et al., 2014). The UBACC is one instrument that provides a protection for MHSU participating in research by providing a rigorous approach to obtaining informed consent (Jeste et al., 2007). The UBACC provides for the identification of individuals who require further assistance in understanding information pertinent to providing informed consent and allows for the researcher to apply remedial action as required by re-teaching unclear areas of study information.

#### **5.3.4.3 Stigma**

The Collins dictionary aptly defines stigma as “something that detracts from the character or reputation of a person” (Collins, 2017), and can be evidenced by stereotyping, prejudicial treatment and discrimination (Corrigan & Watson, 2002). Mental health stigma is often the result of lack of insight and knowledge, and is often perpetuated

by the people closest to the sufferer, including friends and family (Egbe et al., 2014). It poses a significant barrier to help-seeking amongst MHSU, with the fear of being identified as having a mental illness being the greatest contributor to stigma (Clement et al., 2015). Internal stigma, also referred to as self-stigma, occurs when a MHSU emotionally and/or intellectually accepts stereotypes and negative beliefs about mental illness and recognizes these as applying to him or herself (Drapalski et al., 2013). In addition to the impact on help-seeking, the result can include hopelessness, depression, symptomatic deterioration and social withdrawal. External stigma refers to the experience of discriminatory treatment by others, and can be just as damaging as internal stigma (Gray, 2002). This can be discerned from poor treatment of MHSU by medical professionals; neglect, ill-treatment, name-calling, lack of support and assaulted behaviour from family and/or community members (Egbe et al., 2014). Caregivers in my task shifting intervention reported how stigma resulting from the behaviour of the MHSU in their care was burdensome and impacted negatively on their support role. It is thus equally important to keep in mind that the experience of stigma for the families and caregivers of MHSU has adverse outcomes for them as well, specifically psychological morbidity (Grover et al., 2017). The results of this stigma include social exclusion and employment discrimination (Gray, 2002), further contributing to the socioeconomic factors discussed above.

These concerns may spill over into participation in research, where MHSU might be hesitant to participate in research out of a fear of exploitation and discrimination. It has been found that the public are not in favour of research conducted on those with mental illness, citing issues of diminished capacity and exploitation (Muroff, Hoerauf, & Kim, 2006), an authoritarian attitude which was reflected within our CHW group, and which was not shifted by the intervention. This has implications for the consideration of ethics boards, which may be constituted by members not routinely involved in research, as this perspective may introduce bias.

Some suggested interventions to address stigma amongst stakeholders include psychoeducation; increased inclusion of MHSU by family and communities; improved supervision of mental health care providers, better integration of health facilities, and the presence and use of legal frameworks for the handling of instances of discrimination (Egbe et al., 2014). The inclusion of MHSU in the design of the treatment partner intervention was geared largely for this purpose. In line with existing evidence (Mehta et al., 2015), it emerged from my CHW intervention that training does result in some improvement in stigmatizing attitudes amongst CHW. The lack of significant change in authoritarian attitudes however highlights the fact that not all attitudes are easily shifted, pointing to the ongoing work required. While my studies did not focus on targeting stigma as an independent variable, the psychoeducation and training interventions were geared at modifying attitudes towards mental illness, the treatment of mental illness and MHSU. A focused intervention aiming to address stigma needs to be targeted, plausible and provide for intervention reinforcement (Corrigan, 2012).

#### **5.3.4.4 Study design**

##### ***Acceptability and feasibility studies***

Acceptability and feasibility studies have an important role to play in the development of locally appropriate interventions (Spedding, Stein, & Sorsdahl, 2015). The acceptability and feasibility data was drawn from MHSU, their caregivers, mental health support and government stakeholders are an important contributor to securing the potential translatability of the work into policy and the design of clinical services. Cape Town however has unique socioeconomic circumstances, which might limit the generalizability of this feedback for other settings, not just in the rest of LMIC but in South Africa as well. As such, such investigations should ideally be replicated in other similar settings as well.

### ***Qualitative study design***

Qualitative research presents a useful opportunity to access important information, allowing for a valuable understanding of participants' meanings and experiences (Crowe, Inder, & Porter, 2015), echoing themes of justice and self-efficacy. Rich data were gathered from MHSU and caregivers in the design of the treatment partner intervention, the review of which fed directly into both the content of the psychoeducation guide, and the design of the treatment partner and m-health components. Similarly, the final training programme for the CHW intervention was developed following qualitative feedback from the CHW's who received training using the first draft of the training manual. There is ongoing scope for the use of qualitative methods in intervention research, as socio-cultural and economic circumstances provide a rich field of experience from which much can be drawn. Furthermore, the benefit of employing qualitative research in designs that include quantitative methods is the extra depth provided by qualitative data in the interpretation of quantitative data in study designs such as RCTs (Palinkas, 2014).

### ***Randomized controlled trials***

In order to obtain efficacy data (preliminary) for the treatment partner intervention, the RCT study design was adopted, which is regarded as the gold standard for this purpose (Spieth et al., 2016). This design allows for the comparison of an intervention with an alternative intervention or a standard treatment condition, with outcomes measured at set time points. The structured design and reporting processes ensure reproducibility of study procedures and generalizability of findings (Schulz, Altman, Moher, & Group, 2010). In the treatment partner intervention, outcomes of the treatment partner intervention were compared with treatment as usual. Although my findings did not reach statistical significance, the effect favoured the intervention.

### ***Quasi-experiment***

A quasi-experimental design was used for the CHW training intervention, which is an approach that seeks to assess the impact of an intervention on sample without the use of random assignment. The practise-based approach used in delivery of the intervention is one in which the cohort which acts as its own comparison (Handley, Schillinger, & Shiboski, 2011). The baseline data in this case functions as a control for the post-intervention data. The shortcoming of quasi experiments is that it may not be possible to reliably demonstrate a causal link between the intervention and the outcome . It may however, not always be feasible to have a comparison group, as was the case in my trial, as a consequence of study site limitations and service needs. Future work investigating such interventions in similar naturalistic populations may find this approach useful.

#### **5.3.4.5 *Intervention outcomes***

Systematic evaluation of individual MHSU-level outcome has generally been lacking in task shifting interventions (Hanlon et al., 2016). Thornicroft and Slade have presented recommendations for assessing outcomes in mental health research (Thornicroft & Slade, 2014). They propose a taxonomy composed of 8 considerations, framed as decisions. These include 1) deciding whether outcomes should focus (in addition to MHSU) on caregivers, wellbeing of health care staff or members of the public; 2) how outcomes of interest relate to the scientific stage of the investigation; 3) the outcome domain of interest; 4) the envisaged level of assessment; 5) whether outcomes of interest are clinical or recovery-focused; 6) who's perspective is of interest in the investigation e.g. MHSU, community or clinicians; 7) whether investigators are interested in evaluation of deficits and strengths; and 8) whether outcomes assessed will be the same for each participant or individualized.

The interventions in this PhD are Phase 1 studies, in that they assess the tolerability and initial dose response to the delivered interventions. The treatment partner

intervention paid close attention to the outcomes for caregivers and treatment partners (with a focus on the MHSU and caregiver/treatment partner perspective), while the CHW intervention focused more on outcomes for the trained CHWs themselves (with a focus on the CHW perspective). The outcome domains of interest were primarily well-being, adherence behaviour, socioeconomic and mental health services. The focus in the interventions was on the individual intrapsychic level for the CHW intervention, where symptoms and change in knowledge were assessed; and interpersonal for the treatment partner intervention, where the focus was on the caregiver and treatment partner relationships. The CHW training went one step further to assess what might be classified under the broader environmental level of assessment, by evaluating attitudes towards mental illness and MHSU amongst the trained CHW. In the RCT it was important to measure clinical outcomes (change in symptom severity), as well as recovery outcomes; as measured by clinic adherence, readmission, change in unmet needs, and change in medication adherence behaviour.

There was reliance on the perspective of the MHSU and caregivers in the design and conduct of the RCT, from the formative qualitative work to the review of specific components of the intervention and TAU. The CHW's who initially received the finalized CHW training contributed to refinements and the production of the final programme. The main focus was to ensure the training was effective from the perspective of the trainees, a perspective that was carried through in the processes of daily and final training evaluation. From the perspective of the clinician, what would have been most of interest are the clinical outcomes at the end of the RCT. While it was not possible to demonstrate a generalizable result as a consequence of the small sample size, it was possible to show a trend towards improved clinical outcomes such as symptomatic improvement, improved clinic adherence and reduced readmissions for intervention participants

The outcomes for the public were not measured, but these may be implicit in as far as the training of the CHWs might conceivably result in better community-based services for MHSU, and a more informed caregiver may be in a better position to play an advocacy and literacy-sharing role. While it may be possible to conclude that the training was successful in improving knowledge, confidence and attitudes, there is no way to be sure whether this would translate to positive outcomes for the community served. Future work testing such an intervention must be expanded to include service user and service outcomes.

Intervention outcome selection for future studies could therefore be guided by the decision points suggested by Thornicroft and Slade, selecting appropriate outcomes to suit the needs and specific designs of the interventions.

## **5.4 Conclusion**

Task shifting interventions are an important and feasible approach to tackle the resource limitations in Cape Town and settings similar to ours. Interventions must be contextually appropriate and focused on immediate and tangible targets such as adherence and psychoeducation. Additional novel components such m-health continue to have great potential to facilitate access to supervision for cadres, over and above adherence-support functions, but must be carefully tailored to be equally contextually sensitive and appropriate. Fair consideration should be given to self-efficacy and issues of stigma and social inclusion in the design of MHSU-focused interventions. Community health worker training interventions require further evaluation. The evaluation of training programmes that are evidence-based and locally appropriate must include a rigorous evaluation of end-user and health-system outcomes. The rigor of RCTs with more homogenous measures will increase the evidence base and enable better synthesis of evidence in future. The involvement of stakeholders such as government and health facility policy makers, in the generation, evaluation and dispersion of new evidence is likely to facilitate speedier uptake



of best-practice recommendations. The scale-up of services must be undertaken deliberately with due consideration for the impact of changing roles and service burden on existing health workers. Comprehensive planning for the integration of task shifting approaches should include a clear discourse on proactive structural components such as community based support and accessible, appropriate specialized supervision, in line with local legislation. Task shifting present a significant and exciting opportunity to creatively and innovatively extend the reach of mental health services to improve the lot of sufferers and those who care for and support them as we plough forward in our endeavour to achieve mental health for all.

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# Appendices

## Appendix A: Reporting checklists

### PRISMA 2009 Checklist

(Liberati et al., 2009)

Section/topic	#	Checklist item	Reported on Page
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	11
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	viii-xiii
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	11-12
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	13
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	13
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	13-14
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	13-14
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	13-14
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	14

Section/topic	#	Checklist item	Reported on Page
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	14
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	12-13
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	15-16
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	N/A
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	15-16
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
<b>RESULTS</b>			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	17
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	26-34
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome-level assessment (see Item 12).	37-46
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group and (b) effect estimates and confidence intervals, ideally with a forest plot.	47-51
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	37
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
<b>DISCUSSION</b>			

Section/topic	#	Checklist item	Reported on Page
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., health care providers, users, and policy makers).	51-54
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review level (e.g., incomplete retrieval of identified research, reporting bias).	54-55
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	55
<b>FUNDING</b>			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	N/A



## CONSORT Checklist for treatment partner and m-health intervention

(Schulz et al., 2010)

### CONSORT 2010 checklist of information to include when reporting a randomised trial\*

Section/Topic	Item No	Checklist item	Reported on page No
<b>Title and abstract</b>			
	1a	Identification as a randomized trial in the title	56
	1b	Structured summary of trial design, methods, results, and conclusions (for specific guidance see CONSORT for abstracts)	viii-xiii
<b>Introduction</b>			
Background and objectives	2a	Scientific background and explanation of rationale	56-57
	2b	Specific objectives or hypotheses	57
<b>Methods</b>			
Trial design	3a	Description of trial design (such as parallel, factorial) including allocation ratio	57
	3b	Important changes to methods after trial commencement (such as eligibility criteria), with reasons	N/A
Participants	4a	Eligibility criteria for participants	60
	4b	Settings and locations where the data were collected	58-60
Interventions	5	The interventions for each group with sufficient details to allow replication, including how and when they were actually administered	61-66
Outcomes	6a	Completely defined pre-specified primary and secondary outcome measures, including how and when they were assessed	66-69
	6b	Any changes to trial outcomes after the trial commenced, with reasons	N/A
Sample size	7a	How sample size was determined	69
	7b	When applicable, explanation of any interim analyses and stopping guidelines	91-92
Randomization:			
Sequence generation	8a	Method used to generate the random allocation sequence	60-61
	8b	Type of randomisation; details of any restriction (such as blocking and block size)	60
Allocation concealment mechanism	9	Mechanism used to implement the random allocation sequence (such as sequentially numbered containers), describing any steps taken to conceal the sequence until interventions were assigned	60

Section/Topic	Item No	Checklist item	Reported on page No
Implementation	10	Who generated the random allocation sequence, who enrolled participants, and who assigned participants to interventions	60
Blinding	11a	If done, who was blinded after assignment to interventions (for example, participants, care providers, those assessing outcomes) and how	60-61
	11b	If relevant, description of the similarity of interventions	61-67
Statistical methods	12a	Statistical methods used to compare groups for primary and secondary outcomes	72-73
	12b	Methods for additional analyses, such as subgroup analyses and adjusted analyses	72-73
<b>Results</b>			
Participant flow (a diagram is strongly recommended)	13a	For each group, the numbers of participants who were randomly assigned, received intended treatment, and were analysed for the primary outcome	73
	13b	For each group, losses and exclusions after randomisation, together with reasons	73
Recruitment	14a	Dates defining the periods of recruitment and follow-up	69, 73
	14b	Why the trial ended or was stopped	73
Baseline data	15	A table showing baseline demographic and clinical characteristics for each group	76
Numbers analysed	16	For each group, number of participants (denominator) included in each analysis and whether the analysis was by original assigned groups	86-87
Outcomes and estimation	17a	For each primary and secondary outcome, results for each group, and the estimated effect size and its precision (such as 95% confidence interval)	87
	17b	For binary outcomes, presentation of both absolute and relative effect sizes is recommended	87
Ancillary analyses	18	Results of any other analyses performed, including subgroup analyses and adjusted analyses, distinguishing pre-specified from exploratory	87
Harms	19	All important harms or unintended effects in each group (for specific guidance see CONSORT for harms)	N/A
<b>Discussion</b>			
Limitations	20	Trial limitations, addressing sources of potential bias, imprecision, and, if relevant, multiplicity of analyses	92
Generalisability	21	Generalisability (external validity, applicability) of the trial findings	92
Interpretation	22	Interpretation consistent with results, balancing benefits and harms, and considering other relevant evidence	88-92

Section/Topic	Item No	Checklist item	Reported on page No
<b>Other information</b>			
Registration	23	Registration number and name of trial registry	58
Protocol	24	Where the full trial protocol can be accessed, if available	58
Funding	25	Sources of funding and other support (such as supply of drugs), role of funders	xvi

\*We strongly recommend reading this statement in conjunction with the CONSORT 2010 Explanation and Elaboration for important clarifications on all the items. If relevant, we also recommend reading CONSORT extensions for cluster randomised trials, non-inferiority and equivalence trials, non-pharmacological treatments, herbal interventions, and pragmatic trials. Additional extensions are forthcoming: for those and for up to date references relevant to this checklist, see [www.consort-statement.org](http://www.consort-statement.org).

## STROBE Statement—Checklist for reporting of Community Health Worker intervention

(Vandenbroucke et al., 2014)

### STROBE Statement—Checklist of items that should be included in reports of *cohort studies*

	Item No	Recommendation	Reported on Page
Title and abstract	1	(a) Indicate the study’s design with a commonly used term in the title or the abstract	x
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	x-xiii
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	93-95
Objectives	3	State specific objectives, including any pre-specified hypotheses	94-95
Methods			
Study design	4	Present key elements of study design early in the paper	95
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	96,100, 102-106
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	97, 105-106
		(b) For matched studies, give matching criteria and number of exposed and unexposed	n/a
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	104-106
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	104-106
Bias	9	Describe any efforts to address potential sources of bias	95
Study size	10	Explain how the study size was arrived at	95
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	106-107
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	106-107
		(b) Describe any methods used to examine subgroups and interactions	106-115

	Item No	Recommendation	Reported on Page
		(c) Explain how missing data were addressed	108-115
		(d) If applicable, explain how loss to follow-up was addressed	108-115
		(e) Describe any sensitivity analyses	108-115
<b>Results</b>			
Participants	13*	(a) Report numbers of individuals at each stage of study—e.g. numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	107-115
		(b) Give reasons for non-participation at each stage	107
		(c) Consider use of a flow diagram	n/a
Descriptive data	14*	(a) Give characteristics of study participants (e.g. demographic, clinical, social) and information on exposures and potential confounders	107
		(b) Indicate number of participants with missing data for each variable of interest	108-115
		(c) Summarise follow-up time (e.g., average and total amount)	107
Outcome data	15*	Report numbers of outcome events or summary measures over time	108-115
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included	108-115
		(b) Report category boundaries when continuous variables were categorized	n/a
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	108-115
Other analyses	17	Report other analyses done—e.g. analyses of subgroups and interactions, and sensitivity analyses	108-115
<b>Discussion</b>			
Key results	18	Summarise key results with reference to study objectives	126-129
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	129
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	126-129
Generalisability	21	Discuss the generalisability (external validity) of the study results	129

	Item No	Recommendation	Reported on Page
<b>Other information</b>			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	xvi

\*Give information separately for exposed and unexposed groups.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at <http://www.strobe-statement.org>.

## Cochrane Risk of Bias Tool

(Higgins & Green, 2011)

Domain	Description	High Risk of Bias	Low Risk of Bias	Unclear Risk of Bias	Reviewer Assessment	Reviewer Comments
<i>Selection bias</i> <b>Random sequence generation</b>	Described the method used to generate the allocation sequence in sufficient detail to allow an assessment of whether it should produce comparable groups	Selection bias (biased allocation to interventions) due to inadequate generation of a randomized sequence	Random sequence generation method should produce comparable groups	Not described in sufficient detail	<b>High Low Unclear</b>	
<i>Selection bias</i> <b>Allocation concealment</b>	Described the method used to conceal the allocation sequence in sufficient detail to determine whether intervention allocations could have been foreseen before or during enrollment	Selection bias (biased allocation to interventions) due to inadequate concealment of allocations prior to assignment	Intervention allocations likely could not have been foreseen in before or during enrollment	Not described in sufficient detail	<b>High Low Unclear</b>	
<i>Reporting bias</i> <b>Selective reporting</b>	Stated how the possibility of selective outcome reporting was examined by the authors and what was found	Reporting bias due to selective outcome reporting	Selective outcome reporting bias not detected	Insufficient information to permit judgment†	<b>High Low Unclear</b>	
<i>Other bias</i> <b>Other sources of bias</b>	Any important concerns about bias not addressed above*	Bias due to problems not covered elsewhere in the table	No other bias detected	There may be a risk of bias, but there is either insufficient information to assess whether an important risk of bias exists or insufficient rationale or evidence that an identified problem will introduce bias	<b>High Low Unclear</b>	

\* If particular questions/entries were pre-specified in the study's protocol, responses should be provided for each question/entry.

† It is likely that the majority of studies will fall into this category.

Assess each main or class of outcomes for each of the following. Indicate the specific outcome.

Outcome:

Domain	Description	High Risk of Bias	Low Risk of Bias	Unclear Risk of Bias	Reviewer Assessment	Reviewer Comments
<i>Performance bias</i> <b>Blinding (participants and personnel)</b>	Described all measures used, if any, to blind study participants and personnel from knowledge of which intervention a participant received. Provided any information relating to whether the intended blinding was effective.	Performance bias due to knowledge of the allocated interventions by participants and personnel during the study.	Blinding was likely effective.	Not described in sufficient detail	<b>High Low Unclear</b>	
<i>Detection bias</i> <b>Blinding (outcome assessment)</b>	Described all measures used, if any, to blind outcome assessors from knowledge of which intervention a participant received. Provided any information relating to whether the intended blinding was effective.	Detection bias due to knowledge of the allocated interventions by outcome assessors.	Blinding was likely effective.	Not described in sufficient detail	<b>High Low Unclear</b>	
<i>Attrition bias</i> <b>Incomplete outcome data</b>	Described the completeness of outcome data for each main outcome, including attrition and exclusions from the analysis. Stated whether attrition and exclusions were reported, the numbers in each intervention group (compared with total randomized participants), reasons for attrition/exclusions where reported.	Attrition bias due to amount, nature or handling of incomplete outcome data.	Handling of incomplete outcome data was complete and unlikely to have produced bias	Insufficient reporting of attrition/exclusions to permit judgment (e.g., number randomized not stated, no reasons for missing data provided)	<b>High Low Unclear</b>	



## Risk of Bias In Non-randomized Studies - of Interventions

### Bias domains included in the ROBINS-I tool

(Sterne et al., 2016)

Domain	Related terms	Explanation
Pre-intervention	Pre-intervention or at-intervention domains for which risk of bias assessment is mainly distinct from assessments of randomized trials	
Bias due to confounding	Selection bias as it is sometimes used in relation to clinical trials (and currently in widespread use within Cochrane); Allocation bias; Case-mix bias; Channelling bias.	Baseline confounding occurs when one or more prognostic variables (factors that predict the outcome of interest). ROBINS-I can also address time-varying confounding, which occurs when individuals switch between the interventions being compared and when post-baseline prognostic factors affect the intervention received after baseline.
Bias in selection of participants into the study	Selection bias as it is usually used in relation to observational studies and sometimes used in relation to clinical trials; Inception bias; Lead-time bias; Immortal time bias. Note that this bias specifically excludes lack of external validity, which is viewed as a failure to generalize or transport an unbiased (internally valid) effect estimate to populations other than the one from which the study population arose.	When exclusion of some eligible participants, or the initial follow up time of some participants, or some outcome events, is related to both intervention and outcome, there will be an association between interventions and outcome even if the effects of the interventions are identical.
At intervention		
Bias in classification of interventions	Misclassification bias; Information bias; Recall bias; Measurement bias; Observer bias.	Bias introduced by either differential or non-differential misclassification of intervention status. Non-differential misclassification is unrelated to the outcome and will usually bias the estimated effect of intervention towards the null. Differential misclassification occurs when misclassification of intervention status is related to the outcome or the risk of the outcome, and is likely to lead to bias.
Post-intervention	Post-intervention domains for which there is substantial overlap with assessments of randomized trials	
Bias due to deviations from intended interventions	Performance bias; Time-varying confounding	Bias that arises when there are systematic differences between experimental intervention and comparator groups in the care provided, which represent a deviation from the intended intervention(s). Assessment of bias in this domain will depend on the type of effect of interest (either the effect of assignment to intervention or the effect of starting and adhering to intervention).

Domain	Related terms	Explanation
Bias due to missing data	Attrition bias; Selection bias as it is sometimes used in relation to observational studies	Bias that arises when later follow-up is missing for individuals initially included and followed (e.g. differential loss to follow-up that is affected by prognostic factors); bias due to exclusion of individuals with missing information about intervention status or other variables such as confounders.
Bias in measurement of outcomes	Detection bias; Recall bias; Information bias; Misclassification bias; Observer bias; Measurement bias	Bias introduced by either differential or non-differential errors in measurement of outcome data. Such bias can arise when outcome assessors are aware of intervention status, if different methods are used to assess outcomes in different intervention groups, or if measurement errors are related to intervention status or effects.
Bias in selection of the reported result	Outcome reporting bias; Analysis reporting bias	Selective reporting of results in a way that depends on the findings

## Appendix B: Consent and contract forms

### Treatment partner and mobile health formative qualitative consent

**RESEARCH STUDY: Social Inclusion of Patients with Mental Disorders in South Africa, A Randomized controlled trial evaluating the efficacy of a Treatment Partner Intervention Focused on Adherence:**

#### INFORMED CONSENT AND INFORMATION FOR PARTICIPANTS

Hello, my name is..... I work at the University of Cape Town. We are conducting an investigation to find ways of helping patients remember to take their psychiatric medication. We would like to ask you some questions about the relationship between the patient and his/her carer, and ways in which it could be improved to help with taking medication regularly.

#### Participant Rights

If you agree to participate, we would take up about half an hour of your time to talk about these issues. Your participation in this interview is completely voluntary. You are not required to answer any questions that you are not comfortable with. You can also decide to stop participating at any time. Not participating in the group or withdrawing from the group will not disadvantage you in any way. If you agree to participate we will ask you to tell us your thoughts on a series of issues. There is no right or wrong answer to any of the questions. Your opinions and ideas are valuable to us.

To help us in remembering what you say here today, we will be taking notes and would also like to record today's session on tape. Only our research team will review the tape. Your name will not be used as part of any of the results from this study. Your discussion with us will be kept confidential. We would also ask that you do not share anything that has been said during this discussion with anyone. Are you OK with this? Let's go on.

If you have questions about the study you may ask them now. If you don't have any questions and agree to participate in the focus group then we will go ahead and begin. But first, I will ask you to sign this form stating that I, the interviewer, have informed you of your rights as a participant and that you have agreed to participate in today's discussion. This is the only place where your name will be entered.

We thank you for your time. The study has been approved by the Research Ethics Committee of the Faculty of Health Sciences, University of Cape Town. Tel: 021- 406 6496

If you need to contact us to ask us any further questions after the discussion:

Dr Peter Milligan	021 4403 185
Dr Goodman Sibeko	021 4403 185
Dr Sumaya Mall	021 6850 120
Prof Crick Lund	021 6850 120

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Participant Signature

Date

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Interviewer Signature

Date

## **Treatment partner and mobile health participant information and consent form**

### **Participant Information Leaflet and Consent Form**

#### **Social Inclusion of Patients with Mental Disorders in South Africa, A randomized controlled trial evaluating the efficacy of a Treatment Partner Intervention Focused on Adherence**

**Principal Investigator :** Peter D Milligan

Co-Investigators: Dan. J. Stein, Crick Lund, Henk Temmingh, Peter Williams-Ashman, Susan Cleary, Goodman Sibeko (PhD Student), Graham Thornicroft, Ezra Susser

**Address:** Valkenberg Hospital, Observatory Road, Observatory, 7925

Tel: 021 440 3111

You are being invited to take part in a research study. Let's take some time to read over the information about the study together. This will help explain the details of what the study is about. If you have any questions or are confused about anything, please ask the study staff or doctor any questions about any part of this study that you do not fully understand. It is very important that you feel fully satisfied in your understanding of what participating in this study entails. Also, your participation is entirely voluntary. You are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. Nor will it affect the services you are receiving at this clinic. You are also free to withdraw from the study at any point, even if you do initially agree to take part.

This study has been approved by the Human Research Ethics Committee of the Faculty of Health Sciences of the University of Cape Town. This study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

#### **What is this research study all about?**

People with mental illness need to take medication to reduce symptoms and social impairment so that they can be functional and thrive in their own personal lives and communities. It is important to remain compliant to antipsychotic medication for this to occur. This involves going to the clinic as scheduled to receive the medication and to have any arising problems or issues addressed.

Before people are given antipsychotic medications, they receive education about their illness and about medication for mental illness, as well as outpatient follow up which follows discharge, from doctors and nursing staff.

The information people with mental illness get about the illness and antipsychotic medication depends on things like how much time the doctor or nurse spend with them, how the doctor or nurse and the patient relate to each other, and doctor or nurse's skills in talking to people.

Our team has worked on a system to assist users of antipsychotic medication. It provides for education and support to be provided to the mental health care user as well as a treatment partner who assists the user of the medication. The system allows for the use of cellphones which, via an sms system allows us to send and receive information about the taking of medication and attendance at scheduled clinic reviews, as well as other issues which affect the taking of that medication.

The study will be conducted via your local Community Health Centre, as well as our outpatient clinic at Valkenberg Hospital. We plan to test whether people who get assistance from a treatment partner in combination with the cellphone assistance as described above OR by the usual method of discharge and local clinic reviews, take medication and adhere to the discharge plan more reliably. The study aims to include about 120 mental health care users discharged from Valkenberg Hospital Inpatient care.

If you agree to take part, you will sign this form. You will then be interviewed for background information about yourself and your medical history. Then you will be assigned to receive EITHER treatment partner and cellphone intervention OR the usual discharge and local clinic review. We will decide this randomly, like when you toss a coin. No one will be able to influence which group you get assigned to.

All participants will use their existing cellular telephones to receive and send communication to us. This will cost you nothing.

The study will not offer special treatment or medication. If a medical problem arises, you will be referred for appropriate treatment at your nearest appropriate health facility.

#### **What will your responsibilities be?**

You will be required to take your medication as prescribed on discharge from the ward and attend all reviews as scheduled at your local Community Health Clinic on discharge.

If you are assigned to the intervention group, you and your treatment partner will receive sms reminders of the review appointment dates. During your clinic reviews, the nursing staff will send a message to us to inform us of your attendance at review, as well as how regularly you have been taking your medication. They will also take note of any challenges or difficulties you may be experiencing, and assist you accordingly. You will also receive your supply of medication at these visits as usual.

Those who get assigned to the treatment as usual group will be expected to present themselves for review without cellphone prompt reminders. The nursing staff will inform us after 3

months, about your attendance at clinic reviews and how regularly you have taken your treatment. They will also inform us of any challenges or difficulties you have experienced.

Participation in this study requires study staff to access health information in your medical file. Study staff may get additional information about your health and treatment from your medical files. This information includes your medical appointment schedule and attendance. We ask your permission to do so.

**Will you benefit from taking part in this research?**

No benefit can be guaranteed from participating in this project. Participation could however possibly improve how you take care of yourself by helping us to find ways to make sure that issues that affect your adherence to treatment are highlighted and possibly addressed. This could lead to improved health for you.

You may also get some benefit from the study in 2 main ways- first, a detailed health interview will be conducted, which will allow us to diagnose and treat any problems you may have. Second, any problem you have in taking medication will be picked up quickly and you will receive counselling and assistance from the clinic as well as hospital staff.

**Are there in risks involved in your taking part in this research?**

You may find the cellphone notifications inconvenient and annoying. If you do, you may contact the study staff to discuss your problems.

The research study aims to improve how people take care of themselves and adhere to their discharge plan, which includes taking medication as prescribed, as well as attending clinic visits regularly. It is unlikely that it would lead to things getting worse for you.

**If you do not agree to take part, what alternatives do you have?**

Participation in the study is voluntary. You may withdraw from the study at any time. The alternative to participation is the required usual clinic adherence routine. You are free to not participate or to withdraw at any time during the study. Your treatment will not be affected in any way. You may continue to attend your clinic. It would be helpful for the study team to let us know why you have decided not to take part, but you are free to not give a reason.

**Can you be dismissed from the study for any reason?**

It is unlikely that you may be dismissed from the study. If re-admission to hospital is warranted as a consequence of relapse or as a consequence of you being a danger to yourself or others you may be removed from the study subjects. If such a situation arises you will be informed and educated as far as is possible.

**What if you decide that you no longer want to participate in the study?**

Your participation is completely voluntary. You may withdraw from the study at any time. If you do, you will not lose any benefits to which you are otherwise entitled. Withdrawal will not affect the services provided to you in any way.

**Who will have access to your medical records?**

The information collected about you will be treated as confidential and protected. If we write about this work, your identity will remain anonymous. Only the direct study team will have full access to the information. If we need to refer you to a medical team for any reason for treatment, we will provide them with the relevant information needed to treat your condition.

**Is the information you provide confidential?**

All information you provide during the interviews is kept confidential. There are rare times when the law may require us to release your information. We do not anticipate that happening. However, we cannot guarantee it.

All study staff are instructed to keep all of your information secret. They are not allowed to discuss it with anyone outside of your treating team. All study information will be identified by unique identification numbers. All study information and material will be kept safe and confidential. These records will only be available to study staff. Institutional personnel may access it as part of routine audits. A list matching participant names with identification numbers will be kept in a separate secure location. This information will only be available to study staff. Study results will be reported only as a group. This way, no individual participant can be identified.

There are two emergency situations in which study staff may need to identify study participants to others. First, if study staff become concerned that you may harm yourself or another person, they will inform you of their intention to report this to service providers and police authorities who can offer protection to you or others. Second, if the study staff becomes concerned that a child, minor, or older person in your care is experiencing physical or sexual abuse, they will inform you of their intention to report this to service providers and police authorities who can offer protection to you or others.

**Will you be paid to take part in this study and are there any costs involved?**

You will not be paid to take part in the study.

**What if I get injured as a direct result of participating in this study?**

You are unlikely to sustain any injury as a result of this study. In case of an emergency or if you feel you need to contact one of the study doctors you can do so by phoning:

Dr Goodman Sibeko at Tel no 021 440 3111

You can also contact the Human Research Ethics Committee of the Health Sciences Faculty of the University of Cape Town 021 406 6338 if you have any concerns or complaints that have not been adequately addressed by your study doctor.

**Declaration by participant**

By signing below, I ..... agree to take part in a research study entitled *“Social Inclusion of Patients with Mental Disorders in South Africa, A randomized controlled trial evaluating the efficacy of a Treatment Partner Intervention Focused on Adherence”*

**I declare that:**

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is voluntary and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests or in the best interest of others.

Signed at (*place*) ..... on (*date*) ..... 20\_\_.

Signature of participant

**Declaration by treatment partner/associate/ relative of participant (IF UNABLE TO READ OR WRITE)**

By signing below, I .....declare that I have read and understood this consent form about the research study entitled: *“Social Inclusion of Patients with Mental Disorders in South Africa, A randomized controlled trial evaluating the efficacy of a Treatment Partner Intervention Focused on Adherence”*, on behalf of .....(name of participant), and state that he/she understands the study.

.....(relationship to participant)

Signed at (*place*) ..... on (*date*) ..... 20\_\_.



Signature of treatment partner/associate/ relative of participant

**Declaration by investigator/study coordinator**

I (*name*) ..... declare that:

- I have explained the information in this document to .....
- I have encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above

Signed at (*place*) ..... on (*date*) ..... 20\_\_.

Signature of investigator

## Treatment partner contract

### Treatment Partner Information and Consent Form

You have been selected by \_\_\_\_\_ and are being asked to participate in a research study of: ***Social Inclusion of Patients with Mental Disorders in South Africa: A randomized controlled trial evaluating the efficacy of a Treatment Partner Intervention Focused on Adherence***

#### Your role in the study

- To communicate with the patient to ensure he/she keeps to appointment dates and to do your best to encourage the patient take his/her medication as prescribed on discharge from the hospital
- To assist the patient in obtaining the necessary assistance during the treatment period as the need arises
- To receive cellular telephone reminders via sms, of appointment dates to assist the patient
- To seek assistance from the Community Health Clinic where medical or treatment advice is required

You will receive Orientation which will focus on mental health literacy, problem solving, and specific information about the Mental Health service structure and the standard pathways to care, as well as the information about the interventions of the study and on informed consent and confidentiality.

You must be at least 18 years old to participate in this research. Participation in this research project is completely voluntary. You have the right to say no. You may change your mind at any time and withdraw. You may choose to stop participating at any time.

Participating in the study will not cost you anything. There is no financial compensation for participating in this study.

If you have concerns or questions about this study, such as how to do any part of it, or to report an injury or adverse event, please contact the researcher (Dr Goodman Sibeko, Valkenberg Hospital, Department of Psychiatry & Mental Health at Tel: 021 440 3111).

If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, Human Research Ethics Committee, Faculty of Health Sciences, University of Cape Town at Tel 021 406 6338 or Fax 021 406 6411

Your signature below means that you voluntarily agree to participate in this research study.

#### Treatment partner:

I agree to participate in this study. I agree to assist and support \_\_\_\_\_ during the course of this study.

Signature \_\_\_\_\_ Name \_\_\_\_\_ Patient supervised \_\_\_\_\_

Place \_\_\_\_\_ Date \_\_\_\_\_

**Patient:**

I have nominated and agree for the abovementioned to be my Treatment Partner for the above intervention study.

Signature \_\_\_\_\_ Name \_\_\_\_\_ Place \_\_\_\_\_ Date \_\_\_\_\_

## Community health worker training information and consent



### Participant Information Leaflet and Consent Form

#### **Piloting a mental health training programme for community health workers in Cape Town, Western Cape, an exploration of changes in attitude, skills and confidence**

**Principal Investigator: Dr Goodman Sibeko**

Co-Investigators: Dr Goodman Sibeko, Peter Dr D Milligan, Mrs Marinda Roelofse, Mrs Lezel Molefe, Prof Crick Lund, Prof Dan J Stein

**Address:** Valkenberg Hospital, Observatory Road, Observatory, 7925

Tel: 021 440 3111

You are being invited to take part in a research study. This document contains information about the study. If you have any questions or are confused about anything, please do not hesitate to ask the study staff any questions about any part of this study that you do not fully understand. It is important that you feel fully satisfied in your understanding of what participating in this study entails. Your participation in the training component of this study is required as part of the conditions of your employment. However, your participation in the evaluation of the training programme described below is entirely voluntary. You are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do initially agree to take part.

This study has been approved by the Human Research Ethics Committee of the Faculty of Health Sciences of the University of Cape Town. This study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the South African Medical Research Council Ethical Guidelines for Research.

#### **What is this research study all about?**

- People with mental illness need to take medication to reduce symptoms and social impairment so that they can be functional and thrive in their own personal lives and communities. It is important to remain compliant to treatment for this to occur. This involves going to the clinic as scheduled to receive the medication and to have any arising problems or issues addressed.

- It has become apparent that people living with mental illness often do not take their treatment or go to the mental health clinic for necessary review. Community health workers have successfully assisted people with other medical illnesses to remain compliant to their treatment programmes. There is potential for community health worker support to be equally successful in helping to support people living with mental illness. In order to provide this kind of support, community health workers need to be provided with appropriate training in mental health.
- There is currently no standard training programme in mental health for community health workers in South Africa. Our team has developed such a training programme. The training consists of 8 sessions of approximately 3 hours each, with a tea break halfway through each session. It will cover culture and how it impacts on perceptions of mental illness; types of mental illness; substance (drug) use and how it relates to mental illness; the treatment of mental illness, including information about mental health care policy and mental health service user flow in the health care system and the role of the community health worker in the support of people living with mental illness.
- The training sessions will be held on the premises of your current community health worker programme supervisor. We plan to test whether the training programme improves your knowledge and understanding of mental illness, and whether it makes you feel better able to provide assistance to people living with mental illness. We want to find out whether your own views and attitudes towards mental illness are changed in any way by the training programme. At the beginning of the training programme you will be asked to complete a questionnaire which will help us understand how you feel about mental illness, your knowledge of mental illness and how confident you feel about being able to help people with mental illness. We will ask you to complete the same questionnaire at the end of the training. We also want to get your opinion of our training programme. We want to find out which parts of the training are good and which parts of the need improving. In order to collect this information we will ask you complete a brief 5 point questionnaire at the end of each training session, and one final longer questionnaire at the end of the whole training programme.
- If you agree to take part, you will sign this form. You will then be asked to provide us with some basic information about yourself; namely your age, home language and educational level.
- This training will take place during your normal working hours. It will cost you nothing.

**What will your responsibilities be?**

- You will be required to complete the questionnaires as described above to the best of your ability.
- You will be required to attend all the training sessions as required in terms of your employment contract.

**Will you benefit from taking part in this research?**

- We hope that your participation in this programme will result in increased knowledge and understanding of mental illness. We hope that it will enable you to confidently assist people living with mental illness as you encounter them during your work in the community. self-awareness and increased sensitivity for features which may be markers of mental illness.

**Are there in risks involved in your taking part in this research?**

- There are no risks associated with participating in this training programme

- If during your participation in this training programme you should experience a personal event of an extreme emotional nature, we may refer you for evaluation and appropriate assistance. This assistance may be in the form of assistance from your supervisor, referral for counselling, or referral for psychiatric assistance. We ask your permission to do so.

**If you do not agree to take part, what alternatives do you have?**

- Participation in the training programme itself is required by the Western Cape Department of Health, as part of your training requirements. However, participation in the evaluation of the training programme is voluntary. You may withdraw from this voluntary component at any time. Your employment and training will not be affected in any way. It would be helpful for the study team to let us know why you have decided not to take part, but you are free to not give a reason.

**Can you be dismissed from the study for any reason?**

- It is unlikely that you may be dismissed from the study. If an event of a personal nature occurs during the course of training, which deems you unable to complete the programme, you may be removed from the training. If such a situation arises you will be informed and educated as far as is possible.

**What if you decide that you no longer want to participate in the study?**

- Your participation in the training evaluation component is completely voluntary. You may withdraw from the study at any time. If you do, you will not lose any benefits to which you are otherwise entitled. Withdrawal will not affect your employment in any way.

**Who will have access to your personal information?**

- The information collected about you will be treated as confidential and is thus protected. If we write about this work, your identity will remain anonymous. Only the direct study team will have full access to the information. If we need to refer you to a medical team for any reason for treatment, we will provide them with the relevant information needed to treat your condition.

**Is the information you provide confidential?**

- All information you provide is kept confidential. It might happen that we need to refer you for care as mentioned above. In these circumstances we may need to share some of your confidential information as is relevant to assist you. Should this occur, you will be made aware of which information will be shared and with whom.
- All study staff are instructed to keep all of your information secret. All study information will be identified by unique identification numbers. All study information and material will be kept safe and confidential. These records will only be available to study staff. Institutional personnel may access it as part of routine audits. Study results will be reported only as a group. This way, no individual participant can be identified.

**Will you be paid to take part in this study and are there any costs involved?**

- You will not be paid to take part in the study. You do not need to pay anything to be part of this training programme.

**What if I get injured as a direct result of participating in this study?**

- You are unlikely to sustain any injury as a result of this study.

**In case of an emergency** or if you feel you need to contact one of the study team you can do so by phoning:

Dr Goodman Sibeko at Tel no 021 440 3111

You can also contact the Human Research Ethics Committee of the Health Sciences Faculty of the University of Cape Town 021 406 6338 if you have any concerns or complaints that have not been adequately addressed by your study team.

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Declaration by participant

By signing below, I ..... agree to take part in a research study entitled **“Piloting a mental health training programme for community health workers in Cape Town, Western Cape, an exploration of changes in attitude, skills and confidence”**

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in the evaluation component of this programme is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interest..

Signed at (*place*) ..... on (*date*) ..... 20\_\_.

.....

**Signature of participant**

---

Declaration by investigator/study coordinator

I (*name*) ..... declare that:

• I explained the information in this document to .....

• I encouraged him/her to ask questions and took adequate time to answer them.

• I am satisfied that he/she adequately understands all aspects of the research, as discussed above

Signed at (*place*) ..... on (*date*) ..... 20\_\_.

.....  
**Signature of investigator**

---



## Appendix C: Focus Group and individual interview guides

### Caregiver focus group discussion guide

**Interviewer to read:** Thank you for agreeing to participate in this group discussion. We are thinking about a project to help patients take their medication with the help of a treatment partner. A treatment partner can support patients to take their medication. In this group, we would like to ask caregivers for their opinions on such a project. The information you give us will be useful as you all have first- hand experience of caring for someone with mental illness.

#### Caregiver Group

- 1) Could we discuss the diagnosis that the patient you care for has? Do they take medication? If yes, could we discuss their adherence patterns? Are they variable or good?
- 2) Could you describe your role as caregiver? How do you help the patient you care for take their medication regularly?
- 3) Do you think such it would help your relative if they had someone to help them remember to take their treatment?
- 4) In what ways would it be different from the help you are providing at the moment? In what ways could the treatment partner be best equipped to be of assistance to the patient?
- 5) In what ways could a treatment partner relationship be bad?
- 6) Can we discuss the characteristics of a 'treatment partner' partnership? What sort of support would you require to make this relationship effective (Interviewer could probe for cell phone usage etc.:
  - a) How often should a treatment buddy make contact with the patient?
  - b) If they were to make contact, what form should it take, eg a call to see how things are going? a home visit?
  - c) How could such a person strike a balance between keeping their distance and interfering too much?
  - d) How often should cell phone reminder messages be sent?
  - e) Who do you think would be the best person to be a treatment partner for your relative?
- 7) How else could the treatment partner be of assistance?
- 8) Are there any further comments you would like to make?

## Patient focus group discussion and in-depth interview guide

**Interviewer to read:** Thank you for agreeing to participate in this focus group discussion. We are thinking about a project to assist to take their medication by using a treatment partner. A treatment partner can support patients, like yourselves to take their treatment correctly. In this group, we would like to ask patients for their opinions on such a project. The information you give us will be useful as you all have first- hand experience of living with mental illness.

- 1) Could we discuss your diagnosis? What do you think has made you sick?
- 2) What can you no longer do as well as you used to be able to in the past? How does this make you feel?
- 3) How do you feel about having to take medication? Do you regularly take your medication? What has helped you continue to your medication? If you have not been taking your medication regularly, what have been the reasons?
- 4) What do you think you need to help you take your medication and attend clinic appointments more regularly
- 5) How do you feel your family/members of your household can help you take your medication and attend clinic appointments regularly
- 6) Do you think having someone to help with taking your medication would be helpful? In what way?
- 7) In what ways do you think we could assist a treatment partner to become a strong resource/support for you?
  - a) How often should a treatment buddy make contact with the patient?
  - b) If they were to make contact, what form should it take, e.g. a call to see how things are going? a home visit?
  - c) How could such a person strike a balance between keeping their distance and interfering too much?
  - d) How often should cell phone reminder messages be sent?
  - e) Who would you choose as a treatment partner for yourself?
- 8) Apart from helping you with medication, how else do you feel the treatment partner can be of help to you?
- 9) Are there any further comments you would like to make?

## Appendix D: Measures specific to outcomes

### Treatment partner and m-health intervention 3-month interview guide

#### Qualitative Review (3 Months) Guide

##### Steps

- (Informed consent taken at enrolment covers this interview)
- (For the intervention arm, patients are interviewed separately from their treatment partner)
- Thank you for coming for this interview about the study you have participated in. You will be refunded for your transport costs for coming here today.
- This interview should take a maximum of 45 minutes.
- I will ask you a few questions, and then ask you for further information around each question to clarify some issues that may arise.
- Today's interview will be recorded and filed confidentially so that we can later look at and analyse the information together with information from other interviews
- We may be joined by an observer if this is acceptable to you (the interviewee). If you are not comfortable with this we will excuse the observer.
- At the end of the interview you are welcome to ask me any questions you may have. Indeed you may ask for clarifications during the course of the interview as well.

#### Insight, Medication, Attitudes

Can you tell me about your diagnosis

What do you think has made you sick?

What medication are you on?

Have you been taking your medication regularly?

If yes, what has helped you with taking your medication?

If no, what has stopped you from taking your medication? (Probe for side-effects and social stressors)

I'd like to ask you a few questions about your discharge from Valkenberg Hospital 3 months ago..

Treatment as usual group

What information were you given about your diagnosis before leaving the hospital?"

What information were you given about the clinic visits following your discharge?

**The intervention**

Were the sms reminders helpful with remembering to attend the follow up appointments at the clinic?

Were they sent often enough?

Should it be more often?

Should it be less often?

What is the best time of the day to receive an sms notification?

Let's discuss the session when your treatment partner came to the hospital for a meeting with the doctor (investigator) before you were discharged

What information did you get about your diagnosis?

What information did you get about your treatment?

What information did you get about your follow up after discharge?

Was having a treatment partner helpful with taking medication?

If so, how?

If not, why not?

In what ways could the treatment partner support you better?

### **Staff and CHC**

I'd like to ask you a few questions about your experience at the clinic/day hospital.

Is the clinic easy to get to?

Do you know where to go when you arrive at the clinic?

How long did you wait when you arrived for your appointment?

Was this waiting time acceptable?

Let's talk about your interaction with your clinic staff.

Were they easy to talk to? (interviewer can probe further about the attitudes of the staff)

Was the correct medication available for you at your appointment?

If there was a problem with availability was the problem solved to your satisfaction?

Is there anything else that you would like to tell me about your clinic visits?

### **General**

Is there anything else you would like to tell me, which was not covered in the questions above?

**For the treatment partners / carers**

**Adherence**

I would like to ask a few questions about how the patient took his treatment and attended clinic reviews

Has the patient been taking his treatment regularly?
Has the patient been attending clinic review appointments regularly?
What has helped him/her to continue to take their treatment and attend clinic reviews?
What has prevented him/her from taking their treatment and attending clinic reviews?
Was the clinic helpful?  Can you tell me more about that?
How can visiting the clinic be made a better experience?

**Intervention**

I would now like to ask you a few questions about the specific areas we looked at in our investigation/study

**Notifications**

How often did you receive the sms notifications?
Were they clear and easy to understand?
At what time of day did they arrive?
Is this an acceptable time?

Were they helpful? How so?

Were they sent often enough?

Should they be sent less often or more often?

Has being part of this intervention changed things for you and the patient? How?

#### Psycho education

Let's discuss the session when you came to the hospital for a meeting with the doctor (investigator) before the patient was discharged

What information did you get about the patient's diagnosis?

What information did you get about the patient's treatment?

What information did you get about the follow up after discharge?

Was this session helpful? In what way?

In what way can a session like that be improved?

Own role and strength

What has it been like to be the patient's treatment partner?

Which parts of it were good?

Which parts of it were difficult?

How did you make contact with the patient?

How often did you make contact with the patient

What helped you in your role as a treatment partner

What could have helped you be a better treatment partner?

Impact

What was more helpful in reminding the patient to take his treatment and attend clinic appointments? The sms notifications, the psycho education session with the doctor or having a treatment partner? (Probe the carer to rank in order of impact)

Is an intervention of this sort a good idea?

Additional info



## Daily evaluation questionnaire for community health worker training



### **Piloting a mental health training programme for community health workers in Cape Town, Western Cape, an exploration of changes in attitude, skills and confidence**

Goodman Sibeko<sup>1</sup>, Peter D Milligan<sup>1</sup>, Marinda Roelofse<sup>2</sup>, Lezel Molefe<sup>2</sup>, Crick Lund <sup>1</sup>, Dan J Stein<sup>1</sup>

**Trainee Number:**

#### **Daily evaluation form**

1. What did you enjoy most about today?
2. What did you learn today that you feel will help you in your work?
3. Was there anything you did not understand today'? Please give some examples.
4. What did you learn today that was most important to you?
5. Do you have any other comments about today's session?

## Global Assessment of Functioning Scale

(American Psychiatric Association, 2000)

### Global Assessment of Functioning (GAF) Scale

(From DSM-IV-TR, p. 34.)

Consider psychological, social, and occupational functioning on a hypothetical continuum of mental health-illness. Do not include impairment in functioning due to physical (or environmental) limitations.

Code	(Note: Use intermediate codes when appropriate, e.g., 45, 68, 72.)
100   91	<b>Superior functioning in a wide range of activities, life's problems never seem to get out of hand, is sought out by others because of his or her many positive qualities. No symptoms.</b>
90   81	<b>Absent or minimal symptoms</b> (e.g., mild anxiety before an exam), <b>good functioning in all areas, interested and involved in a wide range of activities. socially effective, generally satisfied with life, no more than everyday problems or concerns</b> (e.g. an occasional argument with family members).
80   71	<b>If symptoms are present, they are transient and expectable reactions to psychosocial stressors</b> (e.g., difficulty concentrating after family argument); <b>no more than slight impairment in social, occupational or school functioning</b> (e.g., temporarily failing behind in schoolwork).
70   61	<b>Some mild symptoms</b> (e.g. depressed mood and mild insomnia) <b>OR some difficulty in social, occupational, or school functioning</b> (e.g., occasional truancy, or theft within the household), <b>but generally functioning pretty well, has some meaningful interpersonal relationships.</b>
60   51	<b>Moderate symptoms</b> (e.g., flat affect and circumstantial speech, occasional panic attacks) <b>OR moderate difficulty in social, occupational, or school functioning</b> (e.g., few friends, conflicts with peers or co-workers).
50   41	<b>Serious symptoms</b> (e.g., suicidal ideation, severe obsessional rituals, frequent shoplifting) <b>OR any serious impairment in social, occupational, or school functioning</b> (e.g., no friends, unable to keep a job).
40   31	<b>Some impairment in reality testing or communication</b> (e.g., speech is at times illogical, obscure, or irrelevant) <b>OR major impairment in several areas, such as work or school, family relations, judgment, thinking, or mood</b> (e.g., depressed man avoids friends, neglects family, and is unable to work; child frequently beats up younger children, is defiant at home, and is failing at school).
30   21	<b>Behavior is considerably influenced by delusions or hallucinations</b> <b>OR serious impairment in communication or judgment</b> (e.g., sometimes incoherent, acts grossly inappropriately, suicidal preoccupation) <b>OR inability to function in almost all areas</b> (e.g., stays in bed all day; no job, home, or friends).
20   11	<b>Some danger of hurting self or others</b> (e.g., suicide attempts without clear expectation of death; frequently violent; manic excitement) <b>OR occasionally fails to maintain minimal personal hygiene</b> (e.g., smears feces) <b>OR gross impairment in communication</b> (e.g., largely incoherent or mute).
10   1	<b>Persistent danger of severely hurting self or others</b> (e.g., recurrent violence) <b>OR persistent inability to maintain minimal personal hygiene</b> <b>OR serious suicidal act with clear expectation of death.</b>
0	Inadequate information.

## Clinical Global Impression Scale

(Guy, 1976)

### Clinical Global Impression (CGI)

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**Reference:** Guy W, editor. **ECDEU Assessment Manual for Psychopharmacology. 1976.** Rockville, MD, U.S. Department of Health, Education, and Welfare

#### Rating Clinician-rated

**Administration time** Varies with familiarity with patient

**Main purpose** To provide a global rating of illness severity, improvement and response to treatment

**Population** Adults

#### Commentary

Amongst the most widely used of extant brief assessment tools in psychiatry, the CGI is a 3-item observer-rated scale that measures illness severity (CGIS), global improvement or change (CGIC) and therapeutic response. The illness severity and improvement sections of the instrument are used more frequently than the therapeutic response section in both clinical and research settings. The Early Clinical Drug Evaluation Program (ECDEU) version of the CGI (reproduced here) is the most widely used format, and asks that the clinician rate the patient relative to their past experience with other patients with the same diagnosis, with or without collateral information. Several alternative versions of the CGI have been developed, however, such as the FDA Clinicians' Interview-Based Impression of Change (CIBIC), which uses only information collected during the interview, not collateral. The CGI has proved to be a robust measure of efficacy in many clinical drug trials, and is easy and quick to administer, provided that the clinician knows the patient well.

#### Scoring

The CGI is rated on a 7-point scale, with the severity of illness scale using a range of responses from 1 (normal) through to 7 (amongst the most severely ill patients). CGI-C scores range from 1 (very much improved) through to 7 (very much worse). Treatment response

ratings should take account of both therapeutic efficacy and treatment-related adverse events and range from 0 (marked improvement and no side-effects) and 4 (unchanged or worse and side-effects outweigh the therapeutic effects). Each component of the CGI is rated separately; the instrument does not yield a global score.

#### Versions

CGI for bipolar disorder (CGI-BD), FDA Clinicians' Interview-Based Impression of Change (CIBIC), Clinicians' Interview-Based Impression of Change-Plus (CIBIC+), NYU CIBIC+, Parke-Davis Pharmaceuticals Clinical Interview-Based Impression (CIBI); the CGI has been translated into most languages.

#### Additional references

Leon AC, Shear MK, Klerman GL, Portera L, Rosenbaum JF, Goldenberg I. A comparison of symptom determinants of patient and clinician global ratings in patients with panic disorder and depression. *J Clin Psychopharmacol* 1993; 13(5):327–31.

Spearing MK, Post RM, Leverich GS, Brandt D, Nolen W. Modification of the Clinical Global Impressions (CGI) Scale for use in bipolar illness (BP): the CGI-BP. *Psychiatry Res* 1997; 73(3):159–71.

Zaider TI, Heimberg RG, Fresco DM, Schneier FR, Liebowitz MR. Evaluation of the clinical global impression scale among individuals with social anxiety disorder. *Psychol Med* 2003; 33(4):611–22.

#### Address for correspondence

Not applicable – the CGI is in the public domain.

## Clinical Global Impression (CGI)

### 1. Severity of illness

Considering your total clinical experience with this particular population, how mentally ill is the patient at this time?

- |                             |   |
|-----------------------------|---|
| 0 = Not assessed            | 4 = Moderately ill                        |
| 1 = Normal, not at all ill  | 5 = Markedly ill                          |
| 2 = Borderline mentally ill | 6 = Severely ill                          |
| 3 = Mildly ill              | 7 = Among the most extremely ill patients |

### 2. Global improvement: Rate total improvement whether or not, in your judgement, it is due entirely to drug treatment.

Compared to his condition at admission to the project, how much has he changed?

- |                        |                     |
|------------------------|---------------------|
| 0 = Not assessed       | 4 = No change       |
| 1 = Very much improved | 5 = Minimally worse |
| 2 = Much improved      | 6 = Much worse      |
| 3 = Minimally improved | 7 = Very much worse |

### 3. Efficacy index: Rate this item on the basis of **drug effect only**.

Select the terms which best describe the degrees of therapeutic effect and side effects and record the number in the box where the two items intersect.

EXAMPLE: Therapeutic effect is rated as 'Moderate' and side effects are judged 'Do not significantly interfere with patient's functioning'.

Therapeutic effect		Side effects			
		None	Do not significantly interfere with patient's functioning	Significantly interferes with patient's functioning	Outweighs therapeutic effect
<b>Marked</b>	Vast improvement. Complete or nearly complete remission of all symptoms	01	02	03	04
<b>Moderate</b>	Decided improvement. Partial remission of symptoms	05	06	07	08
<b>Minimal</b>	Slight improvement which doesn't alter status of care of patient	09	10	11	12
<b>Unchanged or worse</b>		13	14	15	16
Not assessed = 00					

Reproduced from Guy W, editor. ECDEU Assessment Manual for Psychopharmacology. 1976. Rockville, MD, U.S. Department of Health, Education, and Welfare

## Medication Adherence Rating Scale

(Fialko et al., 2008)

	Question	Answer
1	Do you ever forget to take your medication?	Yes / No
2	Are you careless at times about taking your medication?	Yes / No
3	When you feel better, do you sometimes stop taking your medication?	Yes / No
4	Sometimes if you feel worse when you take the medication, do you stop taking it?	Yes / No
5	I take my medication only when I am sick	Yes / No
6	It is unnatural for my mind and body to be controlled by medication	Yes / No
7	My thoughts are clearer on medication	Yes / No
8	By staying on medication, I can prevent getting sick	Yes / No
9	I feel weird, like a 'zombie' on medication	Yes / No
10	Medication makes me feel tired and sluggish	Yes / No

## Camberwell Assessment of Needs Scale

(Phelan et al., 1995)

<b>CANSAS-P – Self-rated version of the Camberwell Assessment of Need</b>				
<b>Name:</b>				
<b>Other identifying information (e.g. date of birth):</b>				
<b>Date of completion:</b>				
<p><i>Instructions – please tick one box in each row (22 in total)</i></p> <p><b>No need = this area is not a serious problem for me at all</b>  <b>Met need = this area is not a serious problem for me because of help I am given</b>  <b>Unmet need = this area remains a serious problem for me despite any help I am given</b></p>				
	<i>No need</i>	<i>Met need</i>	<i>Unmet need</i>	<i>I don't want to answer</i>
<b>1. Accommodation</b> <i>What kind of place do you live in?</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>
<b>2. Food</b> <i>Do you get enough to eat?</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>
<b>3. Looking after the home</b> <i>Are you able to look after your home?</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>
<b>4. Self-Care</b> <i>Do you have problems keeping clean and tidy?</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>
<b>5. Daytime activities</b> <i>How do you spend your day?</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>
<b>6. Physical Health</b> <i>How well do you feel physically?</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>
<b>7. Psychotic symptoms</b> <i>Do you ever hear voices or have problems with your thoughts?</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>
<b>8. Information on condition and treatment</b> <i>Have you been given clear information about your medication?</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>
<b>9. Psychological distress</b> <i>Have you recently felt very sad or low?</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>
<b>10. Safety to self</b> <i>Do you ever have thoughts of harming yourself?</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>
<b>11. Safety to others</b> <i>Do you think you could be a danger to other people's safety?</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>

**No need** = this area is not a serious problem for me at all  
**Met need** = this area is not a serious problem for me because of help I am given  
**Unmet need** = this area remains a serious problem for me despite any help I am given

	No need	Met need	Unmet need	I don't want to answer
<b>12. Alcohol</b> Does drinking cause you any problems?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>
<b>13. Drugs</b> Do you take any drugs that aren't prescribed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>
<b>14. Company</b> Are you happy with your social life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>
<b>15. Intimate relationships</b> Do you have a partner?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>
<b>16. Sexual Expression</b> How is your sex life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>
<b>17. Child Care</b> Do you have any children under 18?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>
<b>18. Basic Education</b> Any difficulty in reading, writing or understanding English.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>
<b>19. Telephone</b> Do you know how to use a telephone?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>
<b>20. Transport</b> How do you find using the bus, tram or train?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>
<b>21. Money</b> How do you find budgeting your money?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>
<b>22. Benefits</b> Are you getting all the money you are entitled to?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>

Many thanks for completing the CANSAS-P

© 2007 All rights reserved. The adult CAN was developed by Mike Slade, Graham Thornicroft and others at the Health Service and Population Research Department, Institute of Psychiatry, King's College London, London, UK. CANSAS-P was adapted from the adult CAN by Mike Slade and evaluated by Glen Tobias and Tom Trauer. Further information from [www.iop.kcl.ac.uk/prism/can](http://www.iop.kcl.ac.uk/prism/can).

## Community health worker demographics form



### Piloting a mental health training programme for community health workers in Cape Town, Western Cape, an exploration of changes in attitude, skills and confidence

Goodman Sibeko, Peter D Milligan, Marinda Roelofse, Lezel Molefe, Crick Lund, Dan J Stein

#### Community Health Worker Characteristics

<p>Please complete this form by selecting the response that applies to you and providing any extra information where it is requested. All collected information is confidential and will be used only to understand how the group responds to the training. We need your participant ID number and we do not have access to your name. The information on this form will not be shared with your supervisor.</p>	<p><b>Trainee Number:</b></p>
--	-------------------------------

1 When were you born?

Year:  Month:  Day:

2 When did you start working as a Community Health Worker?

3 What is your highest level of schooling or education?

4 What is your relationship status?

Married	In a committed relationship	Widowed	Separated	Divorced	Single	Other? Describe:
---------	-----------------------------	---------	-----------	----------	--------	------------------

5 How many children do you have

0	1	2	3	4	5	More than 5? How many?	<input type="text"/>
---	---	---	---	---	---	------------------------	----------------------

6 Besides yourself, how many people older than the age of 18 depend on you for money, food or clothing?

0	1	2	3	4	5	More than 5? How many?	<input type="text"/>
---	---	---	---	---	---	------------------------	----------------------



7 How many people between the age of 5 and 18 depend on you for money, food or clothing?

0	1	2	3	4	5
---	---	---	---	---	---

More than 5? How many?

--

8 How many people under the age of 5 depend on you for money, food or clothing?

0	1	2	3	4	5
---	---	---	---	---	---

More than 5? How many?

--

9 Do you take treatment for diabetes, high blood pressure or any other medical condition?

Yes	No
-----	----

If yes, which one?

--

10 Do you take treatment for any psychiatric illness?

Yes	No
-----	----

If yes, which one?

--

11 How many people in your home suffer from any medical illness, like diabetes, high blood pressure, etc.

0	1	2	3	4	5
---	---	---	---	---	---

More than 5? How many?

--

12 How many people in your home suffer from any psychiatric illness?

0	1	2	3	4	5
---	---	---	---	---	---

More than 5? How many?

--

13 Do you have another job in addition to your community health work?

Yes	No
-----	----

If yes, what is it?

--

14 Have you have had any other jobs before starting your community health work?

Yes	No
-----	----

f yes, what work did you do?

Are you retired?

Yes	No
-----	----

15 s there anything else you would like to tell us about yourself?



**Piloting a mental health training programme for community health workers in Cape Town, Western Cape, an exploration of changes in knowledge, attitude and confidence**

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**Pre-Training Case Vignettes**

On this sheet you will find five case scenarios. Please read through the case and answer the questions that follow for each, in the space provided. After the 5 cases there are four short questions. Please answer these in the space provided as well.

Brenda

Brenda started feeling more and more sad after her sister died in a car accident. The whole family had been affected by this tragic loss, but Brenda's sadness seemed to last the longest. Some six months after her sister's death, she was still unable to stop thinking about the loss. She generally felt worthless and hopeless. She found it difficult to fall asleep. She lost 10kg in weight, had very little energy, and had trouble concentrating. At work, she found herself crying at inconvenient times.

1. What illness do you think Brenda might have?
2. What type of medication might help her?
3. Besides medication, what else can be done to help Brenda?
4. What would be your role as a community health worker in a case like this?

## Shane

Shane is 20 years old. His behaviour has changed from what it was before. He has been irritable and short tempered, laughing uncontrollably at strange times, and talking more than usual and faster than usual. He has also been having unusual thoughts and drinking more alcohol. For the past 2 weeks, he has missed classes at varsity. He has been staying up most nights until 4 or 5 a.m. He claims to be writing 2 novels at the same time and another book about his life, which he says will make him millions. He denies using any drugs, but he admits to using more alcohol recently. When his family tries to help and support him, he reacts angrily and accuses them of trying to control him and suppress his greatness.

1. What illness do you think Shane might have?
2. What type of medication might help him?
3. Besides medication, what else can be done to help Shane?
4. What would be your role as a community health worker in a case like this?

## Fred

Fred is 25 years . He has been doing very well in his career as an insurance salesman. For the past few months his manager has noticed a great decrease in his performance. When asked about this, he said that his mind was no longer fully on his work. He told people that he had become more in touch with his spiritual side. He said that he could hear and see beings from "beyond the other side". Because of this he was aware of an important plot by evil spirits that want to destroy the world. He even received some messages about this while watching television or listening to radio. Fred also had difficulty concentrating, wasn't making much sense when he spoke, and that he often appeared to lose touch with reality.

1. What illness do you think Fred might have?
2. What type of medication might help him?
3. Besides medication, what else can be done to help Fred?
4. What would be your role as a community health worker in a case like this?

## Nandi

Nandi was driving to work one day when all of a sudden she felt intense fear. Her heart started to beat hard and very fast. She felt short of breath. Her hands were sweating and her knees were trembling. She felt as though she was about to die. She immediately stopped the car, got out and stood at the side of the road. After about 10 minutes, she felt more in control again. This had happened to her before and she worried about it happening again. She also worried a lot about things in general. Her intense worry often affected her work and relationships.

1. What illness do you think Nandi might have?
2. What type of medication might help her?
3. Besides medication, what else can be done to help Nandi?
4. What would be your role as a community health worker in a case like this?

## Jerome

Jerome started drinking heavily every weekend during his student days. By the time he had graduated and married he was drinking on a daily basis. Although his wife insisted that he drank too much, Jerome argued that he remained in control. Nevertheless, his work and appearance gradually deteriorated to the point that his supervisor at work began to suspect that he might be drinking on the job. A few months later he was involved in a serious car accident, where he wrote off two cars. The police who arrived at the scene of the accident insisted that his blood be taken for alcohol analysis. In view of the fact that his alcohol level far exceeded recommended levels, Jerome was found negligent and his license was taken away from him. Only at that point did he agree to seek help.

1. What diagnosis do you think Jerome might have?
2. What type of treatment might help him?
3. Besides medication, what else can be done to help Jerome?
4. What would be your role as a community health worker in a case like this?

Please answer these Questions in the space provided:

1. How would you know that someone wants to end his or her own life? (Suicidal)

2. What should you do if you think someone wants to end his or her own life?

3. What should you do if someone is aggressive and dangerous?

4. When would someone with a mental illness need to be admitted to the hospital

## Post-Training Case Vignette

Trainee Number:



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#### Post Training Case Vignettes

On this sheet you will find five case scenarios. Please read through the case and answer the questions that follow for each, in the space provided. After the 5 cases there are five short questions. Please answer these in the space provided as well. Please feel free to write at the back of the page if you require more space.

#### 1. Jessica

Jessica is a 28-year-old married doctor, a high achiever. Lately she has been having feelings of worthlessness and shame due to not being able to perform as well as usual.

She is very tired and generally has very low energy. She has been finding it difficult to concentrate at work. Even her coworkers have noticed that she has become irritable and withdrawn, which is unlike her. She has been calling in sick a lot, and just sits and watches TV when home. She is not interested in sex or any form of intimacy with her husband, but doesn't want to admit to not feeling fine. She has had thoughts of suicide but has never actually attempted to end her own life. She is generally dissatisfied with her life, and feels hopeless.

- What is the most likely diagnosis?
- What treatment should this person receive?
- What other help should this person get?
- What advice would you give this person?
- What is your role as a community health worker in this case?

## 2. Patricia

<p>Patricia is a 38-year-old divorced mum with two teenage children. She works as a very senior matron at Groote Schuur Hospital. In spite of being very good at her job she worries constantly about losing her job and not being able to provide for her children. Worrying a lot has been a problem for the past 8 months. Because of this she has constantly been restless, tired and tense.</p> <p>She paces up and down in her office when no one is around and has at times lost track of what she was saying in meetings. At bedtime can't stop thinking about all the terrible things that could happen, like losing her job and ending up homeless.</p>	<ul style="list-style-type: none"><li>a) What is the most likely diagnosis?</li><li>b) What treatment should this person receive?</li><li>c) What other help should this person get?</li><li>d) What advice would you give this person?</li><li>e) What is your role as a community health worker in this case?</li></ul>
---	---

## 3. Tshepo

<p>Tshepo is a 21-year-old student at UCT. His friends have noticed increasingly bizarre behaviour from him over the past few weeks. He often appears to be speaking to someone even when there is no one there. He refuses to answer the phone because he believes it will activate a radio that has been inserted into his brain by the police in order to follow him around. He has refused his parents' suggestion to go to the psychiatrist to be assessed. He believes that his parents are conspiring with aliens to remove his brain and put it in their own head. He no longer attending lectures and has fallen behind other students. Tshepo does not drink or use any drugs. He has an aunt who has been in and out of psychiatric hospitals over the years due to unpredictable and bizarre behaviour.</p>	<ul style="list-style-type: none"><li>a) What is the most likely diagnosis?</li><li>b) What treatment should this person receive?</li><li>c) What other help should this person get?</li><li>d) What advice would you give this person?</li><li>e) What is your role as a community health worker in this case?</li></ul>
---	---



#### 4. Martin

<p>Martin is 35 years old. He has lost his job due to coming to work drunk and performing badly. He has previously sold things from his grandmother's home to buy drugs. He is therefore now unemployed and homeless. He has charges against him for drug possession and an assault, which took place while he was intoxicated.</p> <p>Both Martin's parents were drug addicts and he experienced physical, sexual, and emotional abuse throughout childhood at their hands. His father died of liver disease at the age of 37. Martin first used alcohol at age 14. He began using other drugs, including mandrax and dagga by age 16 and Tik by age 19. He uses Tik the most and feels he cannot function without it. He often gets very ill when he is unable to get hold of tik. He has lost friends as a result of his tik use. In spite of all this, he continues to use drugs</p>	<ul style="list-style-type: none"><li>a) What is the most likely diagnosis?</li><li>b) What treatment should this person receive?</li><li>c) What other help should this person get?</li><li>d) What advice would you give this person?</li><li>e) What is your role as a community health worker in this case?</li></ul>
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#### 5. Michael

<p>Michael is 21 years old. He is very talkative, short tempered and irritable. He has even been arrested for aggressive behaviour. He has reported feeling that his thoughts were going very fast, and struggled to focus. Generally feels he is very wealthy and very famous in spite of evidence that this isn't true. He has high energy levels and has difficulty falling asleep. He doesn't need much sleep though. He feels and functions just fine on just an hour or two of sleep per night. He used to be very sad in the past and kept to himself a lot at that time. Now he feels quite the opposite at times, and claims he has amazing new ideas to save the poor in the world. He uses a lot of dagga and other drugs while irritable or very happy.</p>	<ul style="list-style-type: none"><li>1) What is the most likely diagnosis?</li><li>2) What treatment should this person receive?</li><li>3) What other help should this person get?</li><li>4) What advice would you give this person?</li><li>5) What is your role as a community health worker in this case?</li></ul>
---	---

## 6) General questions

1. When is a person admitted as a voluntary admission?

2. When is a person admitted as an assisted admission

3. When is a person admitted as an involuntary admission?

4. What is the role of the police in an admission?

5. What are some of the issues that affect older people?

## Mental Health Knowledge Schedule

(Evans-Lacko et al., 2010)



Trainee Number:

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#### Mental heAlth Knowledge Schedule (MAKS)

*Instructions: For each of questions 1-6 below, respond by circling one answer only. Mental health problems here refer, for example, to conditions for which an individual would be seen by healthcare staff.*

1. Most people with mental health problems want to have paid employment.	Agree Strongly	Agree Slightly	Neither Agree nor disagree	Disagree Slightly	Disagree Strongly	Don't Know
2. If a friend had a mental health problem, I know what advice to give them to get professional help.	Agree Strongly	Agree Slightly	Neither Agree nor disagree	Disagree Slightly	Disagree Strongly	Don't Know
3. Medication can be an effective treatment for people with mental health problems.	Agree Strongly	Agree Slightly	Neither Agree nor disagree	Disagree Slightly	Disagree Strongly	Don't Know
4. Psychotherapy (e.g., talking therapy or counselling) can be an effective treatment for people with mental health problems.	Agree Strongly	Agree Slightly	Neither Agree nor disagree	Disagree Slightly	Disagree Strongly	Don't Know
5. People with severe mental health problems can fully recover.	Agree Strongly	Agree Slightly	Neither Agree nor disagree	Disagree Slightly	Disagree Strongly	Don't Know
6. Most people with mental health problems go to a healthcare professional to get help.	Agree Strongly	Agree Slightly	Neither Agree nor disagree	Disagree Slightly	Disagree Strongly	Don't Know

*Instructions: For each of questions 7-12, say whether you think each condition is a type of mental illness by circling only one answer*

7. Depression	Agree Strongly	Agree Slightly	Neither Agree nor disagree	Disagree Slightly	Disagree Strongly	Don't Know
8. Stress	Agree Strongly	Agree Slightly	Neither Agree nor disagree	Disagree Slightly	Disagree Strongly	Don't Know
9. Schizophrenia	Agree Strongly	Agree Slightly	Neither Agree nor disagree	Disagree Slightly	Disagree Strongly	Don't Know
10. Bipolar disorder (manic-depression)	Agree Strongly	Agree Slightly	Neither Agree nor disagree	Disagree Slightly	Disagree Strongly	Don't Know
11. Drug addiction	Agree Strongly	Agree Slightly	Neither Agree nor disagree	Disagree Slightly	Disagree Strongly	Don't Know
12. Grief	Agree Strongly	Agree Slightly	Neither Agree nor disagree	Disagree Slightly	Disagree Strongly	Don't Know

## Mental Health Nursing Clinical Confidence Scale

(Bell, Horsfall, & Goodin, 1998)



Trainee Number:

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### Mental Health Nursing Clinical Confidence Scale

For each statement below, please circle the response that applies to you.

1. I can communicate effectively with clients with a mental health problem.	Strongly agree	Agree	Disagree	Strongly disagree
2. I can assess the psychosocial circumstances of clients.	Strongly agree	Agree	Disagree	Strongly disagree
3. I can assess the mental state of a client.	Strongly agree	Agree	Disagree	Strongly disagree
4. I can develop a nursing care plan on the basis of my assessment.	Strongly agree	Agree	Disagree	Strongly disagree
5. I can assist clients with a mental illness to clarify treatment goals.	Strongly agree	Agree	Disagree	Strongly disagree
6. I am able to provide basic counseling for clients with a mental illness.	Strongly agree	Agree	Disagree	Strongly disagree
7. I am able to be empathic with a range of clients with a mental illness.	Strongly agree	Agree	Disagree	Strongly disagree
8. I can provide information and education for clients regarding their mental health diagnosis.	Strongly agree	Agree	Disagree	Strongly disagree
9. I am able to assist clients to develop life skills.	Strongly agree	Agree	Disagree	Strongly disagree
10. I have a basic knowledge of antipsychotic medications and their side effects.	Strongly agree	Agree	Disagree	Strongly disagree
11. I have a basic knowledge of antidepressants and their side effects.	Strongly agree	Agree	Disagree	Strongly disagree
12. I have a basic knowledge of anti-anxiety medications and their side effects.	Strongly agree	Agree	Disagree	Strongly disagree
13. I have a basic knowledge of mood stabilizers and their side effects.	Strongly agree	Agree	Disagree	Strongly disagree
14. I am able to provide client education regarding the effects and side effects of medications.	Strongly agree	Agree	Disagree	Strongly disagree
15. I can fit in with the nursing team in the discussion of a client with mental illness.	Strongly agree	Agree	Disagree	Strongly disagree
16. I can contribute client-related mental health information at a treatment team meeting.	Strongly agree	Agree	Disagree	Strongly disagree
17. I can handle clients who are verbally aggressive.	Strongly agree	Agree	Disagree	Strongly disagree
18. I can handle clients who are physically aggressive.	Strongly agree	Agree	Disagree	Strongly disagree
19. I am able to establish my own personal boundaries when relating to clients with a mental illness.	Strongly agree	Agree	Disagree	Strongly disagree
20. I can seek support from other members of the mental health team, including my supervisor.	Strongly agree	Agree	Disagree	Strongly disagree

## Community Attitudes Towards The Mentally Ill Scale

(Taylor & Dear, 1981)

Trainee Number



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### Community Attitudes Towards The Mentally Ill Scale

The following statements express various opinions about mental illness and about people with mental illness. Mental illnesses are medical conditions that disturb a person's thinking, feeling, mood, the way the person relates to others, and the person's daily functioning. Please circle the response that most accurately describes your reaction to each statement. It's your first reaction, which is important. Don't be concerned if some statements seem similar to ones you have previously answered.

Please be sure to answer all statements. Please circle the response that applies to you.

a)	As soon as a person shows signs of mental disturbance, he or she should be hospitalized	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
b)	More tax money should be spent on the care and treatment of adults with mental illness	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
c)	An adult with mental illness should be kept away (isolated) from the rest of the community	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
d)	The best therapy for many adults with mental illness is to be part of a normal community.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
e)	Mental illness is an illness like any other.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
f)	Adults with mental illness are a burden on society.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
g)	Adults with mental illness are far less of a danger than most people think.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
h)	The presence of mental health facilities like clinics and hospitals in a residential area downgrades the village.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
i)	There is something about adults with mental illness that makes it easy to tell them from normal people.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
j)	Adults with mental illness have for too long been the subjects of ridicule.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
k)	A woman would be foolish to marry a man who has suffered from mental illness, even though he seems fully recovered.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
l)	As far as possible mental health services should be provided through community-based facilities.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree


**Trainee  
Number:**

m) Less emphasis should be placed on protecting the public from adults with mental illness.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
n) Spending more on mental health services is a waste of tax money.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
o) No one has the right to exclude adults with mental illness from their village.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
p) Having adults with mental illness living within a village might be good therapy for them, but the risks to residents are too great.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
q) Adults with mental illness need the same kind of control and discipline as a young child.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
r) We need to adopt a far more tolerant attitude toward adults with mental illness in our society.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
s) I would not want to live next door to someone who has been mentally ill.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
t) Residents should accept the location of mental health facilities in their village to serve the needs of the local community.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
u) Adults with mental illness should not be treated as outcasts of society.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
v) There are enough existing services for adults with mental illness.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
w) Adults with mental illness should be encouraged to assume the responsibilities of normal life.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
x) Local residents have good reason to resist (to be against) the location of mental health services in their village.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
y) The best way to handle adults with mental illness is to keep them behind locked doors.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
z) Our mental hospitals seem more like prisons than like places where adults with mental illness can be cared for.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
aa) Anyone with a history of mental illness should be excluded from taking public office (like being a ward councillor or town mayor).	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
bb) Locating mental health services in a village does not endanger local residents.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
cc) Mental hospitals are an out-dated means of treating adults with mental illness	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree


**Trainee  
Number:**

dd) Adults with mental illness do not deserve our sympathy.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
ee) Adults with mental illness should not be denied their individual rights.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
ff) Mental health facilities should be kept out of residential villages.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
gg) One of the main causes of mental illness is a lack of self-discipline and will power	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
hh) We have the responsibility to provide the best possible care for adults with mental illness.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
ii) Adults with mental illness should not be given any responsibility.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
jj) Residents have nothing to fear from people coming into their village to obtain mental health services.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
kk) Virtually anyone can become mentally ill.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
ll) It is best to avoid anyone who has mental problems.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
mm) Most women who were once patients in a mental hospital can be trusted as baby sitters.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
nn) It is frightening to think of people with mental problems living in residential village.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

## Community Health Worker Training Evaluation



### Piloting a mental health training programme for community health workers in Cape Town, Western Cape, an exploration of changes in attitude, skills and confidence

Goodman Sibeko<sup>1</sup>, Peter D Milligan<sup>1</sup>, Marinda Roelofse<sup>2</sup>, Lezel Molefe<sup>2</sup>, Crick Lund<sup>1</sup>, Dan J Stein<sup>1</sup>

#### Training Evaluation

Please circle the response that most closely represents how you feel about the statement on the left. This will help us understand how you have experienced the training.

The Training						
1. The information in the sessions was relevant to my training.	Not applicable	Strongly disagree	Disagree	Cannot Decide	Agree	Strongly agree
2. The training was long enough to cover all the topics.	Not applicable	Strongly disagree	Disagree	Cannot Decide	Agree	Strongly agree
3. The training was done in a way that made me feel comfortable to speak and contribute.	Not applicable	Strongly disagree	Disagree	Cannot Decide	Agree	Strongly agree
4. The training provided chances for me to ask questions and understand what was taught.	Not applicable	Strongly disagree	Disagree	Cannot Decide	Agree	Strongly agree
5. The information in the training was easy for me to understand.	Not applicable	Strongly disagree	Disagree	Cannot Decide	Agree	Strongly agree
Instruments and Processes						
6. The icebreaker helped me to feel relaxed and ready to learn.	Not applicable	Strongly disagree	Disagree	Cannot Decide	Agree	Strongly agree
7. The PowerPoint slides and discussions helped me learn.	Not applicable	Strongly disagree	Disagree	Cannot Decide	Agree	Strongly agree
8. The daily evaluation helped me think through what I had learnt.	Not applicable	Strongly disagree	Disagree	Cannot Decide	Agree	Strongly agree
The trainer						
9. The trainer was prepared for the training sessions.	Not applicable	Strongly disagree	Disagree	Cannot Decide	Agree	Strongly agree
10. The trainer was understood the information she was teaching.	Not applicable	Strongly disagree	Disagree	Cannot Decide	Agree	Strongly agree
11. The trainer answered questions well and was good at managing the group.	Not applicable	Strongly disagree	Disagree	Cannot Decide	Agree	Strongly agree



12. The trainer made the training sessions interesting.	Not applicable	Strongly disagree	Disagree	Cannot Decide	Agree	Strongly agree
13. The trainer communicated clearly.	Not applicable	Strongly disagree	Disagree	Cannot Decide	Agree	Strongly agree
14. The trainer encouraged participation and interaction.	Not applicable	Strongly disagree	Disagree	Cannot Decide	Agree	Strongly agree
Training setting						
15. The training space was suitable for learning.	Not applicable	Strongly disagree	Disagree	Cannot Decide	Agree	Strongly agree
16. The training location was easy to find.	Not applicable	Strongly disagree	Disagree	Cannot Decide	Agree	Strongly agree
Benefit						
17. I needed training on mental illness	Not applicable	Strongly disagree	Disagree	Cannot Decide	Agree	Strongly agree
18. The training was relevant to improving the knowledge and skills I need to accomplish my job.	Not applicable	Strongly disagree	Disagree	Cannot Decide	Agree	Strongly agree
19. The case studies were helpful and helped me see how I will actually perform in the field.	Not applicable	Strongly disagree	Disagree	Cannot Decide	Agree	Strongly agree
Overall						
20. I am satisfied with the training course.	Not applicable	Strongly disagree	Disagree	Cannot Decide	Agree	Strongly agree
21. I am satisfied with the trainer	Not applicable	Strongly disagree	Disagree	Cannot Decide	Agree	Strongly agree
22. I am satisfied with the training environment.	Not applicable	Strongly disagree	Disagree	Cannot Decide	Agree	Strongly agree
23. Additional Comments:						